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Choices made under reproductive uncertainty: acceptance or rejection of amniocentesis by women at genetic reproductive risk

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Choices made under reproductive uncertainty: Acceptance or rejection of amniocentesis by women at genetic reproductive risk

by

Carol A. Gosselink

A Dissertation Submitted to the
Graduate Faculty in Partial Fulfillment of the
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DEDICATION

To Adam, firstborn, favorite son, only child,
and joy of my life--

To my mother, who has nurtured and supported me--

And to the memory of my father, who would have been
proud that, with this dissertation, all four of
his children have completed their doctorates--

This dissertation is dedicated.

ACKNOWLEDGEMENTS

If my behavior is at all indicative of others', acknowledgement pages are little read, much less appreciated. However, having accomplished a Herculean task, and fully realizing this would not have been possible without the support, guidance, and advice of many people, I am compelled to acknowledge these worthy individuals even if I end up being the only one who fondly gazes on these pages.

First, I must thank my major professor, Dr. Willis J. Goudy, who was my champion during my tenure at ISU and who tendered edifying and prompt guidance on my dissertation despite the fact that he himself was operating under a very tight time schedule. I am also grateful to Drs. Patricia Keith, Ron Simons, Vern Ryan, and Joyce Mercier, who have assisted me in their various roles as professors, references, role models, and committee members.

Next, I wish to acknowledge three ISU faculty members who had no obligation to help me, but did so nevertheless. To Dr. Betty Dobratz, a special thanks for all the many ways you enabled me to achieve this educational goal, especially for helping me forge through the maddening complexities of JCL and WYLBUR and encouraging me to continue when I was inclined to curse the darkness rather than turn on a computer. To Dr. Danny Hoyt, who embodied what a mentor should be--thank you for your guidance and unselfish sharing

of papers, ideas, time, computers, and, most importantly, your friendship. My appreciation also goes to Dr. Carl Roberts, whose assistance on a bleak and rainy afternoon helped shed light on a dimly-understood computer run.

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Finally, to my favorite sister and confidant, and to all my friends on shore who were convinced and therefore convinced me that, despite all odds, I would beat the June 5th deadline, my heartfelt appreciation.

EPIGRAM

Listen to me, little fetus,
Precious homo incompletus,
As you dream your dreams placental
Don't grow nothing accidental!

Budding off the primal egg
Grow one tiny, bulbous leg.
Swept along by nature's tide,
Grow one on the other side--
Swiveled in its proper hip.
And, here's a useful baby tip:
Though you may really think you oughtn't
Grow lungs, which hardly seem important
In your snug and sodden sac
Later on you'll feel their lack.

Heed me well, oh precious progeny!
Recapitulate phylogeny
In your amniotic lake
Don't grow nothing by mistake.

(Jerry Adler, 1987a)

CHAPTER I: INTRODUCTION

The concept of genetic disease is not new. As early as the fifth century A.D., Hebrew law not only acknowledged the existence of hemophilia but also recognized it as a disorder that affected males but was transmitted by females (Hendin and Marks, 1978). Two millennia later, the groundwork for modern genetics was laid by Gregor Mendel, who studied inheritance patterns of recessive and dominant genes (Wagner, 1981). Subsequently, geneticists have identified over 2,800 single gene diseases caused by alterations in functions of the genetic code and hundreds of chromosomal disorders or other multifactorial congenital anomalies, which are associated with the interaction of environmental factors and genetic predispositions (McKusick, 1978). Finally, with the advent of modern medical technologies, a new and rapidly expanding field of prenatal diagnosis of birth defects became firmly established in the biological sciences.

The medical, legal, and sociological consequences of these technological advances have not gone unnoticed. Concerns about ethical ambiguities alone have spawned heated debates about prenatal diagnosis and genetic counseling.

The focus of this study, however, is largely confined to examining the impact these new techniques exert on women at reproductive risk in the planning of their families. Specifically, this research proposes to identify social identity, normative, and reference group factors that influence women to accept or reject amniocentesis.

Amniocentesis, an antenatal diagnostic test whereby fetal cells are obtained for biochemical and/or chromosomal analysis, is a medical procedure that was pioneered in the late 1960s (Nadler, 1968; Pernoll et al., 1974). The first intrauterine diagnosis of a chromosomal anomaly occurred in 1967 (Jacobson and Barter, 1967). By 1978, a National Institute of Health study confirmed that amniocentesis performed between the 15th and 18th week of pregnancy provided parents and health-care professionals with a relatively safe and accurate means of detecting prenatal chromosomal abnormalities, neural tube defects, disorders of enzyme production or functioning causing abnormal metabolism, and X-linked (transmitted through the female chromosomes) disorders (Lowe et al., 1978; Davies, 1983). Within 13 years of the first prenatal diagnostic test, Simpson et al. (1980) estimated that more than 100,000 amniocenteses had been performed.

The risk of spontaneous abortion as the result of amniocentesis ranges from only 0.2% to 1.5% (Golbus et al.,

1979; Cruikshank et al., 1983). In light of this, the procedure has become more widely accepted and advocated, particularly for women age 35 and older who are at higher genetic risk for conceiving infants with Down syndrome (trisomy 21). Older women thus represent about three-fourths of those most often referred for genetic testing (Marion et al., 1980; Davies and Doran, 1982).

Negative results from amniocentesis testing do not guarantee the birth of a healthy baby. Although prenatal diagnosis can be 99.5% accurate given the availability of good laboratory facilities (Davies, 1983), a majority of congenital anomalies still cannot be detected prenatally (Council on Scientific Affairs, 1982). It has been estimated that 20% of the abnormal infants born each year, 50% of the spontaneous abortions, 20% of the pediatric hospitalizations, and 40% of all childhood deaths are attributable to genetic abnormalities (Fraser, 1969; Day and Holmes, 1973). Nevertheless, amniocentesis has the potential for informing parents about the presence or absence of certain congenital diseases. In fact, the President's Commission on Mental Retardation (Adams et al., 1981) predicted that by the turn of the century, the number of infants born with genetic disorders causing severe mental retardation could be reduced by half through the use of prenatal genetic diagnosis. Yet, estimates on the

percentage of women in groups with genetic risks who avail themselves of this service ranges from only 5% among rural, black, low socioeconomic status women to a high of 65% for highly educated white women with upper level incomes who live in urban areas; about 20-25% is the most likely appraisal for the eligible population (Sokol et al., 1980; Adams et al., 1981; Sepe et al., 1982).

Discerning factors that influence patients to accept or reject antenatal genetic screening has been of considerable interest to social scientists and genetic counselors alike. Logically, it would seem that by fully utilizing the services available to them, prospective parents have the opportunity to maximize their chances of having a normally-functioning child. Anxieties relating to known hereditary problems or risks associated with advanced maternal age can be allayed by negative test results; for women who find they are carrying an affected fetus, the information offers them a choice of either terminating the pregnancy or becoming emotionally prepared in advance for the birth of a child with a genetic disease. In reality, however, empirical evidence reveals prenatal genetic diagnosis to be a potentially stressful procedure that often engenders anxiety (Beeson and Golbus, 1979; Phipps and Zinn, 1986a), anticipatory grief (Brewster, 1984), anger (Phipps and Zinn, 1986b), hostility (Fava et al., 1983; Elkins et

al., 1986), depression (Antley, 1977), and significant marital distress (Blumberg et al., 1975). Avoidance of antenatal screening does not necessarily relieve these tensions, particularly if the parents are aware of their increased genetic risks. Reproductive uncertainty, resentment (Lippman-Hand and Fraser, 1979a,b), denial (Hsia, 1979), or guilt (Kessler et al., 1984) are among some of the painful reactions experienced by individuals who refuse genetic prenatal diagnosis.

This wide range of responses suggests the need for thoughtful research that takes into account social identity, attitudinal, and normative reference group factors that affect the decision-making processes and choices of women at genetic risk. The current study, then, is undertaken with the objective of reexamining factors previously identified in reproductive-choice research as well as investigating new or little-studied facets that relate to the ultimate rejection or acceptance of amniocentesis.

Significance of the Study

Factors influencing the acceptance or rejection of amniocentesis are not well understood. Prenatal diagnosis of genetic anomalies represents a major scientific achievement. It is responsible for reducing the number of children born with Down syndrome and has provided older

women the security of knowing delayed or postponed reproduction need not necessarily entail significantly higher risks of bearing a child with trisomy 21. However, there are still substantial segments of the eligible population that do not seek out the procedure because of fear or as a result of their beliefs, misinformation, or lack of knowledge. Geneticists and health educators can thus profit from the findings of this study relating to the acceptance or rejection of prenatal diagnosis. Such information could lead to the formulation of new approaches to genetic counseling and outreach programs. Results obtained from analysis of the data could be useful in educating the public in general about family planning options and the place of amniocentesis within the constructs of such planning.

Current trends in marriage and fertility patterns are particularly relevant to the applicability of the research question at hand. The recent rise in age at marriage and the decline in first birth rates within marriage, while representing a return to earlier family formation patterns (Thorton and Freedman, 1983), increase the likelihood that first-time mothers will be at higher risk for conceiving a child with congenital anomalies. Down syndrome is of primary concern here, since its risk ratio increases from about 1:1,667 live births at maternal age 20 to 1:60 by age

40 and 1:9 for those 49 years of age (Hook, 1981). Moreover, as Hook (1981) demonstrated, there is a fairly linear progression of increased risks for several chromosomal abnormalities as maternal age rises, further underscoring the advisability of prenatal diagnostic screening among older pregnant women.

A wide acceptance of amniocentesis could reduce or conceivably eliminate the birth of genetically-affected children to mothers at reproductive risk. This could significantly diminish both personal and public health-care expenses in a society already burdened with burgeoning health-care costs and shrinking fiscal resources. By examining factors that influence acceptance or rejection of prenatal diagnosis, this study may likewise find methods of relieving the anxieties or reducing the reluctance of prospective mothers with respect to the procedure.

Amniocentesis and genetic counseling both offer potentials for averting or mitigating the burden of raising a congenitally-affected child. Parents who are aware of their odds of reproductive risk may elect to avoid pregnancy, may become pregnant with the knowledge that the pregnancy can be terminated if the child is affected, or may be better prepared in advance to deal with the consequences of raising a child with chromosomal anomalies. However, if patients reject amniocentesis or genetic counseling, they

foreclose on these options of choice in reproductive decision-making. It is essential, then, to identify barriers, whether structural, social, or attitudinal, that prevent prospective clients from seeking genetic counseling services.

Similarly, the present research has the utility of helping genetic counselors modify or tailor their consultations to the particular needs of the parents seeking their assistance. Factors that may actually complicate genetic counseling interactions and choices should be delineated to alert counselors to any changes that need to be made to facilitate the transfer of information to the counselees (subjects at genetic risk). Foreknowledge of how certain attitudinal, normative, or self-identity variables affect the reception of information may improve counselors' communications and their abilities to help prospective parents achieve a decision with which they will be satisfied. It is therefore vital that geneticists become familiar with these factors.

The sociological implications of the study are also relevant. In determining the weight and extent of normative, social identity, and reference group variables, the potential exists for building sociological theories and models that can better explain consumer behavior in health-oriented settings. Very little applied theory has

evolved to explain the actions of clients in genetic counseling situations and what has been done is often too limited. For example, the preponderance of studies have been guided by rational decision-making and subjective utility models to explicate reproductive choices under conditions of uncertainty. However, by focusing on and expecting logical or rational explanations rather than exploring attitudinal and emotional factors that influence behaviors, the decision-making processes of real-world situations are obscured.

The study has the singular advantage of examining both rejectors and acceptors of amniocentesis, affording a comparison group that will facilitate the identification of important differences between these two groups. Finally, this research is distinctive in that it proposes not only to investigate variables denoted in previous studies, but to explore more closely the impact and significance of social network and normative influences heretofore little examined in the genetic counseling literature.

The Present Study

An exploratory analysis of multiple factors suggested by previous research will be undertaken in the present study to achieve a better understanding of the correlates of rejection or acceptance of amniocentesis. Differences

between acceptors and rejectors of amniocentesis will be examined using baseline data compiled between July, 1981, and June, 1983, from 249 respondents. The University of Iowa Hospitals and Clinics is the main office for a five-region genetic consultation service covering the state of Iowa, which provides evaluation, diagnosis, and counseling for genetic diseases. From the clientele referred to this service, 199 acceptors and 29 rejectors of amniocentesis were solicited for participation in the study; an additional 21 cooperating rejectors were recruited statewide through obstetricians and gynecologists practicing in Iowa. The information is available from face-to-face interviews conducted with these individuals after they had decided to accept or reject amniocentesis but before the procedure (in the case of the acceptors) had been performed.

The study is proposed with several objectives in mind. First, an attempt will be made to identify malleable factors that may increase a client's willingness to undergo amniocentesis. Second, sociostructural, nonmalleable factors that influence decisions and outcomes will be specified and explored, since a recognition of these factors is essential to better understand the influences that form counselees' decisions. Finally, implications for genetic counseling relating to decision-making and choices in prenatal testing will be addressed.

The format for the proposed study is as follows. Chapter Two presents the theoretical orientation guiding the dissertation and reviews empirical research investigating significant predictors of the acceptance or rejection of prenatal diagnostic procedures. The literature is summarized and theoretical hypotheses are derived. Chapter Three outlines the methods and procedures to be used in the study. The basic research design, sample characteristics, conceptual measures, and operationalized hypotheses will be reviewed and statistical procedures will be discussed. Chapter Four presents results of the analysis and Chapter Five summarizes and discusses these findings. In this chapter, too, implications for applied significance and utility as well as suggestions for future research will be delineated. Finally, in an Epilogue, the focus will move from a sociology <u>in</u> medicine approach to a sociology <u>of</u> medicine analysis. In this section, comparisons between medical and sociological perspectives, practices, methods, and interpretations will be made with the objective of contrasting the differences, denoting the similarities, and suggesting ways of extracting the best of both worlds to establish a fruitful, symbiotic research relationship between the two disciplines.

CHAPTER II: LITERATURE ON GENETIC COUNSELING

As medical technology and genetic knowledge progressed, the prevailing hope was that birth defects could eventually be eliminated or at least greatly reduced. As Carter (1979:1798) optimistically predicted, "There are good prospects of achieving a substantial reduction in the proportion of...handicapped children by genetic counseling supplemented with prenatal diagnosis." However, with time, it has become increasingly apparent that knowledge and technology have little to do with pregnancy planning because the people who ultimately make the decisions regarding the undertaking and/or outcome of pregnancy are potential parents, not emotionally removed geneticists or doctors. Thus, researchers from the fields of medicine, genetics, sociology, psychology, and anthropology have begun exploring factors relating to the decision-making processes of people seeking genetic counseling.

The findings generated by these diverse fields of study and far-ranging theoretical perspectives are varied and sometimes contradictory. Within this chapter, previous guiding frameworks, assumptions, and research findings will be discussed. First, however, to better understand the development of genetic counseling, a brief synopsis of its

history will be included and the theoretical orientation proposed for the current study will be outlined. A comprehensive literature review of prior findings will provide guidance in generating hypotheses within which factors influencing the decisions of genetic counselees can be explored given the theoretical perspective of the current study. The chapter will conclude by combining the theoretical concepts to form the general hypotheses to be tested. General models diagramming these posited relationships will be developed.

Theoretical Orientation

Theoretical orientations used to study the decisions and behaviors of people eligible for genetic counseling have emanated from the diverse fields of medicine, psychology, economics, anthropology, and sociology. Some researchers have employed larger formal theories while others have tested middle-range theories or models in an attempt to gain a clearer understanding of the processes involved. Still, no predominant perspective has emerged. Part of the problem related to the shifting paradigms researchers and counselors have embraced in the practice and study of genetic counseling and its clientele. As Kuhn (1970) explained it, a paradigm leads researchers to identify the important questions, explanatory principles, models, and criteria for

acceptance or rejection of findings consistent with the school of thought or research tradition the paradigm represents. Kuhn noted that when a particular paradigm comes into "fashion," much of the research is conducted using that perspective. However, when a paradigm changes, usually when it has lost its explanatory power because new evidence suggests it is insufficient or incomplete, research perspectives also shift; findings or trends discovered under one paradigm are generally no longer applicable in the new paradigm. When a new paradigm gains supremacy in a field of study, the preponderance of research will take that perspective until the new paradigm has reached its limits and another one replaces it.

The study and application of human genetics has undergone three major paradigmatic shifts in the past eighty years (Caplan, 1979; Kessler, 1980). Kessler suggested that a central core of beliefs has persisted through each shift (i.e., that the provision of genetic education is a primary objective of genetic counseling). However, implementation of this core of beliefs has varied considerably over time. The eugenics paradigm of the early-to-middle twentieth century was largely motivated by a social Darwinistic perspective. Legislation restricting immigration and sterilization of mentally-retarded individuals was the overt manifestation of this paradigm (Ludmerer, 1972; Allen,

1975), while individual, nonmedical counselors stressed defense of the human gene pool rather than individual needs (Lappe, 1973; Twiss, 1979). Humans were perceived as rational beings who were motivated by a sense of duty and obligation to the future to seek genetic counseling (Muller, 1958).

By the 1940s, disillusionment with the excesses of the eugenics movement prompted scientists to turn to a preventive medicine paradigm. With its medicalization, genetic counseling was seen as legitimate only when provided by a physician and the traditional doctor-patient relationship was stressed. Here, the counselor was the advice-giver and counselees, motivated by fear of repetition of a genetic problem or the desire to comply with the doctor's referral, were passive recipients of the counselor's instructions. Counselors maintained control, authority, and power in the relationship while the patients assumed the compliant behavior associated with Parsons' (1951) newly-formulated "sick role." Over time, the style of communication advocated for the physician within a counseling relationship under this paradigm shifted away from directive to interactive. However, as Kessler (1980) noted, this meant that doctors had to relinquish their knowledge-based superior status and adopt a stance of neutrality. This shift created tensions not only for the

doctor but for those patients who expected their physicians to provide more guidance than the accepted position of neutrality would allow.

By 1972, it became apparent that neither the eugenics nor preventive medicine paradigms were very successful (Hecht and Holmes, 1972). Both paradigms either tacitly or explicitly emphasized prevention, which placed the counselor in the position of "protecting the social good at the expense of individual prerogatives" (Kessler, 1980:169). Practical considerations also suggested that these perspectives were not highly successful. Given the limitations of technology, preventing genetic disease was not realistic; at-risk persons were not always willing to enter into genetic counseling (Beck et al., 1974); counselees often failed to understand or remember information disseminated in counseling sessions (Sorenson, 1974); and their expressed intentions regarding reproduction were often at variance with what they actually did (Antley, 1979b). Finally, and most importantly, practitioners in the field began to acknowledge that genetic counseling involves highly-charged emotional issues that require the counselor to deal with human thinking, feeling, and behavior. Thus, the psychologically-oriented paradigm emerged. Within this perspective counselors have recognized that individuals entering genetic counseling come with their own belief

systems, attitudes, values, and norms. Counselees are not passive recipients of information dispensed from a knowledgeable resource person. To the contrary, they actively process the information and rely on their own interpretations of the "objective" realities they encounter in a counseling situation.

The psychologically-oriented paradigm is now in popular ascendancy in the study of genetic disease. It is appropriate, therefore, to undertake the investigation of factors influencing the decision-making process of subjects who choose or reject amniocentesis with the guidance of a theoretical perspective that acknowledges the necessity of examining the individual's sense of self, her values and attitudes, and the impact of social groups and societal norms if one hopes to understand human behavior. Symbolic interactionism offers such a framework.

Symbolic interactionism draws on the writings of Scottish moral philosophers, who believed society was a network of interpersonal communications and who viewed humans as more than biological animals reacting to their environment (Stryker, 1981). From American pragmatists, symbolic interactionism adopted the premise that people develop a sense of self through interaction with others (James, 1890; Cooley, 1902) and with the pre-existing social order (Dewey, 1940), and that if individuals "define

situations as real, they are real in their consequences" (Thomas and Thomas, 1928:567). Mead (1934) is credited with establishing symbolic interactionism as one of sociology's primary theoretical frameworks. Blumer (1969), an enthusiastic student of Mead, wrote extensively about symbolic interactionism, taking Mead's rather vague ideas and making his own interpretations. Later, Kuhn (1964) developed another school of symbolic interactionism, one that, unlike Blumer's perspective, was more deterministic in nature and was inclined to use quantitative, traditional scientific research methods. Some other closely related perspectives emanating from symbolic interactionism included the study of normative or comparison reference groups (Shibutani, 1955; Festinger, 1954) and dramaturgy (Goffman, 1959).

Each of these branches represents somewhat different perspectives, so much so that the infighting and criticisms among the various schools of symbolic interactionism would suggest that there is little in common (e.g., Blumer, 1978; Brittan, 1973). Still, there are several basic tenets of symbolic interactionism that most advocates, to varying degrees, hold to be true. First, individuals act based upon meaning. Second, meaning is emergent, arising from interaction with others by taking on the role of others; therefore, society is not a static structure but a process

in which people are interacting, adjusting, redefining, and reconstructing reality. Third, at the same time, the meaning of human conduct reflects an overarching core of shared, common, consensual interpretations (i.e., significant symbols that emanate from and represent the cultural whole). Fourth, consciousness or thinking involves interaction with the self, where an individual dialogues between an impulsive self and a generalized other, which represents the perspective of the individual's reference group or larger society. And, fifth, humans are participants in creating their own destinies; human conduct influences and is influenced by antecedent events, significant others, and the cultural whole (Manis and Meltzer, 1978).

From symbolic interactionism and its various offshoots, then, this study will draw on several concepts. Individuals define reality and interpret their situations by engaging in "minded" behavior in which they deliberately select the stimulus to which they respond (Mead, 1934). The world is objective and resistant to efforts to change it, but when attempting to understand human behavior, one must examine individuals' perceptions and their definitions of meaning (Wilson, 1983). Symbolic interactionism accepts that people are creators of their world, though not in circumstances of their choosing. Individuals are part of a sociocultural

complex and must cope with the constraints the situation imposes on them.

An individual's perception of meaning arises from the processes of communication, negotiation, and interaction with others (Menzies, 1982). Certain primary groups more than others provide a frame of reference for individuals. These groups help individuals define norms, develop a perspective or reality, and validate their construction of the social world, which includes their values, beliefs, attitudes, or opinions (Cooley, 1902; Shibutani, 1955; Festinger, 1954). Reference groups also provide a resource for social comparison to help individuals validate their social construction of and sociostructural position in the world (Festinger, 1954; Maines, 1977; Rosenberg and Pearlin, 1978; Rosenberg, 1981; Stryker, 1981; Wills, 1981, 1985; Boyce, 1985).

Goffman (1963) developed the "sensitizing concept" that individuals with an attribute that is perceived as somehow discrediting are stigmatized and are thus affected and often limited in their interactions with others. This stigmatized perception of self may distort reality and interpretation of the situation. Stigmatized individuals may also deny their stigmatized status rather than incorporate the damaging perception of a discrediting status into their sense of self.

While symbolic interactionism offers a rich framework within which actions and interpretations of people interacting with significant others can be investigated, it has not been without its critics. For instance, symbolic interactionism has been faulted for failing to explore the emotional aspects of the social actors (Menzies, 1982; Stryker, 1981). However, the contention made in this study is that focusing on "minded" behavior does not, of necessity, eliminate considerations of the emotional realm of human reality. Some sociologists, such as Shott (1979) and Hochschild (1979), already have provided symbolic interactionist accounts of how the meaning of people's emotions is shaped by their situation. Within this study, too, the emotional aspects of the participants deciding whether to undergo genetic testing cannot be ignored, since decisions relating to childbearing are more often emotional than "rational."

Further criticisms are directed at symbolic interactionism because it has not generally been perceived as a highly-testable or causal theory. Menzies (1982:25), for example, pointed out that irreconcilable tensions arise between competing schools or perspectives of symbolic interactionism because the Blumerian or Chicago school holds that symbolic interactionism provides a "volunteristic, interpretative description and as such has a significant

contribution to make to sociology." The methods advocated by those who wish to apply more conventional research techniques within a symbolic interactionism framework are, Menzies suggested, inappropriate and a source of considerable dispute among symbolic interactionists. Blumer (1956) railed against sociological analysis that relies on "generic" variables, which in his view are indistinct, abstract, and, for purposes of understanding participants' definitions and interpretive processes, very limited. Becker and Geer (1957) similarly noted that using interview instruments rather than participant observation tends to distort the findings; interviewers have only one point in time from which to draw conclusions and this can lead to errors of inference because the interview questions are not always able to elicit the subjects' true feelings, definitions, and interpretations.

The position taken in this study, however, is that symbolic interactionism can in fact be operationalized and that the methods employed need not be confined solely to the observational techniques embraced by earlier notable symbolic interactionists (e.g., Becker, 1953; Emerson, 1970; Goffman, 1961; Whyte, 1943). Kuhn's University of Iowa school of symbolic interactionism advocated a scientific, positivistic stance. He believed the "key ideas of symbolic interactionism could be operationalized and utilized

successfully in empirical research" (Kuhn, 1964:72). It is contended that for this study, Kuhn's more empirical approach is in order for four primary reasons. First, because of the extensive research that has gone on before, much of it qualitative, some "sensitizing" concepts relating to genetic counseling clientele and their decision-making processes have already been delineated. Blumer (1956), perhaps, would maintain that no universal variables can be identified since persons distinctively define their own situations. However, the assumption guiding this study is that while individual reality is unique, persons facing the same situation--that of deciding about reproduction and prenatal diagnosis--have certain salient traits, characteristics, or responses in common. Thus, in selecting variables already shown to influence outcomes of reproductive decision-making, the processual and interpretive essence of the action is maintained but for purposes of research is operationalized into concepts that can be tapped using interview techniques.

Second, by using a standardized instrument, this research will attempt to avoid some of the biases of interpretation and dissimilarities of interaction that might arise in open-ended or observational studies. Huber (1973), for example, insisted that there is a potential for bias any time a researcher follows the methodological teachings of

Blumer. A "blank mind," she suggested, affords fertile ground for the research largely to reflect the perspective of the researcher. To make things worse, because the study cannot be replicated, there are no safeguards. Each symbolic interactionist description stands on its own, with no check on individual researcher bias. It is true that by adopting interview methods, the interpretation of the data is limited to a single time frame. Although inferences may be made, the interpretation of respondents' answers will largely be confined to their expressed answers and behaviors given the context of the interview. This may limit the larger perspective. Yet it affords a more consistent reference point for comparison across participants who were studied during a two-year period. Using a standardized instrument also guards against the natural tendency for a researcher to vary or alter techniques, questions, or inquiries given the information already gathered from earlier interactions with respondents.

Third, statistical analysis of data does not reveal ultimate truths. It tends to obscure individual idiosyncratic behaviors or definitions. Nevertheless, it affords a basis for comparison with other research undertaken in the same way. Rather than distinguishing individualistic and unique concepts, using statistical analysis allows for larger generalizations and the

accumulation of a knowledge base relating to participants' stable social identity elements, norms, attitudes, and beliefs to their reproductive behaviors and decisions. Thus, the claim of its devotees, that more than any other theory symbolic interactionism establishes the linkage between the individual and larger social and cultural structures, can more readily be reviewed employing statistical techniques to help discern these linkages.

Finally, by virtue of the personnel, time, and financial constraints involved, it is necessary to rely on a standardized questionnaire format enabling the investigation of a somewhat larger sample than conventional observational techniques generally allow. As Lofland (1978) pointed out, the problem of "analytic interruptus" is common to symbolic interactionists; the time and effort required to do thorough, insightful analysis often lead to shallow, narrow case studies and little accumulated knowledge. By relying on more "conventional" positivistic, empirical methods, this study is undertaken with the prospect that somewhat larger, generalizable, and comparable results will be found, which may provide a useful springboard for future research in this area.

While not an advocate of empirical analysis, Menzies (1982:36) concluded that "whatever methodology is used--from participant observation to surveys--it must be done with a

sensitivity to the integrity of the world that one is trying to describe." The current study will attempt to adhere to this premise.

Review of the Literature

Dependent variable: decision under reproductive uncertainty

Acceptance or rejection of amniocentesis The dependent variable to be explored is acceptance or rejection of prenatal diagnostic testing. The preponderance of research over the past fifteen years has tried to determine which factors influence women in their reproductive decisions (Antley, 1976; Levine, 1979). The primary mission of genetic counseling research under the eugenics or preventive medicine paradigms had been to make sure women at reproductive risk were aware of their risks and that they would act "accordingly," which meant either foregoing reproduction or taking the necessary precautions (e.g., undergoing prenatal diagnosis) to avoid bearing children with genetic disorders. Within the psychologically-oriented paradigm, genetic counselors view their objective to be that of assisting prospective parents through the decisions they face given their at-risk status. The processes of interpretation a potential mother undertakes can be envisioned as a "decision tree" (Figure 1), where at each juncture the woman selects her course of action from among

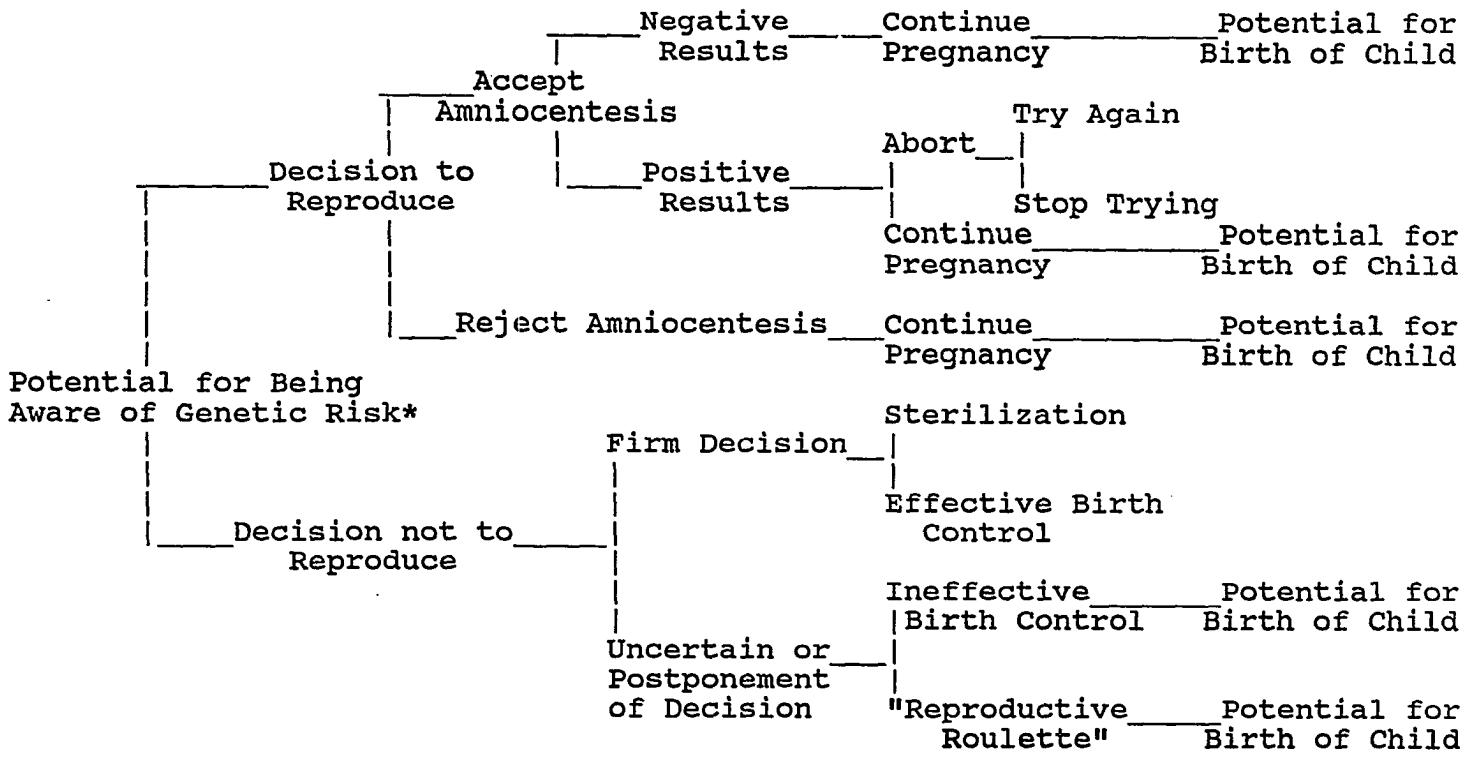

Figure 1. Decisions made under conditions of reproductive uncertainty**

*For illustrative purposes, awareness of one's genetic reproductive risk is assumed to be a given, although research indicates such knowledge in fact is highly variable. Within the current study, exposure to (but not necessarily acceptance or understanding of) information regarding at-risk status was only a given after the subjects had decided to reproduce and had become pregnant.

**Adapted from Pauker and Pauker (1979).

two or more alternatives (one of the options always being the decision not to decide). This conceptualization of the process is particularly relevant to a symbolic interactionist perspective, which holds that humans constantly define meaning and determine their actions based on interaction with significant others or with the self (the generalized other). While not specified within the decision tree, these significant others, the normative standards they convey, and the concept of self all undoubtedly influence the woman's definition of meaning and subsequent action at each stage of decision making.

In the present study, 249 women who were eligible for amniocentesis either because of advanced maternal age or familial genetic disorders decided to accept or reject prenatal testing. Although, as the decision tree suggests, acceptance or rejection of amniocentesis is only at the beginning of the many options and alternatives pregnant, at-risk mothers must interpret and act upon, this will be the focus of the current research. Drawing on the vast body of research literature, an attempt will be made to identify factors that cause the pregnant women to achieve their resolutions regarding amniocentesis. It is with this exploration of decision outcome in mind that relevant research will be reviewed in this section.

Independent variables related to decision outcome

Drawing on the interpretations of various symbolic interactionists, three major concepts that are predicted to relate to the acceptance or rejection of amniocentesis will be explored. From the perspective of Kuhn (1964), Stryker (1959, 1980), and Rosenberg (1981), literature relating to stable social identity elements as they represent the self will be examined. Research analyzing the importance of reference groups as providers of motivational, emotional, informational, or spiritual support (Boyce, 1985; Wills, 1985) will be reviewed. Finally, studies examining the interpretation of meaning of genetic risk information as it applies to the women's definition of the situation and literature investigating the norms individuals use to guide their decisions will be discussed.

Social identity elements: the self The social identity of patients in genetic counseling needs to be considered when determining outcomes and influences (Antley and Hartlage, 1976). Drawing on Kuhn's (1964) concept of a basic, stable sense of self, and from Stryker's (1959:114) explanation of actors' "positions," which "are socially recognized categories...serving to classify persons," several variables that influence the counselees' decision-making processes and interpretations will be reviewed.

Education One of the most consistent findings in genetic counseling research is that women who seek antenatal diagnosis are more highly educated than are those who refuse or are unaware of genetic testing services (Antley, 1977; Nielsen, 1981; Davies, 1983). Roghmann et al. (1983) noted that about one-fourth of the mothers 35 or older with less than high school education accepted genetic counseling and amniocentesis, as compared with more than half of those with graduate degrees. In Antley's (1977) sample, eight out of nine clients with above-high school education, as opposed to nine of nineteen individuals with high school or less education understood their diagnosis and correctly identified their recurrence risks after counseling. Kaback et al. (1974) explored reasons motivating individuals to seek genetic counseling and screening tests and found a positive correlation with educational level.

Education appears to reflect several factors that may relate to the use of antenatal testing. Not only does higher education suggest the ability to receive and retain new information, it may also represent the faculty to seek out information or to know relevant resources. Emery et al. (1979) noted that self-referrals for genetic counseling in Britain increased from 20% in 1973 to 60% in 1976, often because the subjects had read an article on medical genetics

or had seen a television documentary program. Seidenfeld et al. (1980) speculated that formal education increases the likelihood that individuals would have been exposed to fundamental information necessary to grasp genetic concepts and probabilities (e.g., biology, Mendelian inheritance patterns); more importantly, higher education may train individuals to define a problem, explore possible alternative actions, and weigh the costs and benefits of each action. These skills would then assist them in deciding what information was necessary and where the information could be referenced. Meeker (1980) concurred, noting that people with higher levels of education are in a better position to acquire accurate information about the kinds of technical, medical, financial, or psychological consequences of childbearing than are persons with less education. Essentially, "people with higher levels of education have already invested in the tools with which to acquire information. For them, part of the costs of collecting information is already paid" (Meeker, 1980:29). Harper (1983) noted that the ideal time for initial genetic counseling establishing risk factors to occur would be before conception. He (1983:308) concluded, "Unfortunately, though, this applies only to the few informed and articulate couples who are aware of a genetic risk and are able to obtain advice regarding it."

Results offered by Sorenson et al. (1981) may suggest yet another facet of higher education that has not been discussed previously. They found that higher education alone didn't necessarily predict learning of genetic information. Their study demonstrated that clients with graduate or college level education who entered counseling without knowing their diagnosis or risk were no more likely than were clients with junior high or high school educational levels to retain the information disseminated during counseling. Similarly, Wertz et al. (1984) confirmed that learning of medical facts did not appear to reduce clients' uncertainty, nor did prior knowledge about genetic risks. Yet those with higher rates of education were more likely to accept genetic diagnostic procedures. Thus, education may actually be more indicative of a certain preference about lifestyle or management of issues than of a specific ability to understand and manipulate genetic risk knowledge as it applies to the individuals involved.

Education is generally strongly correlated with higher socioeconomic status, which is also associated with higher use of genetic testing (Roghmann et al., 1983). None of this suggests that women of lower educational attainment and/or lower socioeconomic status cannot similarly be made aware of their risks, as research by Marion et al. (1980) revealed. In their study, 522 low-income and

little-educated obstetric patients received genetic counseling; 61% of the 157 who were eligible for and were offered amniocentesis accepted the procedure, a higher rate than is often seen even among the most educated eligible groups. Yet of the 120 who were at risk because of advanced maternal age, only 5% had reported any prior knowledge of this risk. Given this context, lower education and/or socioeconomic status may indicate lower access to and knowledge about genetic diagnostic services or genetic risk, but not necessarily more resistance to the procedure once the objective facts are known. Supporting this, Lippman-Hand and Piper (1981) and Sell et al. (1978) reported that prior familiarity with genetic risks and amniocentesis increased the likelihood that women would hold favorable opinions about prenatal diagnosis.

Finally, drawing on health behavior literature, Kirscht (1977) found a strong socioeconomic status gradient in health-promoting behavior. He noted that income is important when cost is a barrier, but that education is the much more salient predictor of health-promoting behavior. But, he cautioned, there will always be "specific, situational, and normative aspects" that will shape individual behavior and interpretations (1977:161).

Spouse's education In a related vein, much of the research that included information about the spouse's

education level has found it to be a significant predictor of recalling risk probabilities correctly and that the higher the education level of their husbands, the more likely were women to recollect their risks two years after counseling. Only 45% of those whose husbands had no high school as compared with 74% of those whose husbands held university degrees remembered the risk correctly. This finding is in keeping with Stryker's (1959) assertion that when an individual interprets the meaning of a situation and processes this information, more weight or priority is given to the perspectives of certain significant others. Hence, for a woman seeking prenatal genetic diagnosis, the "position" of and interaction with her husband may influence her understanding and retention of the information received. This, in turn, may lead to an easier processing of information and an acceptance of prenatal diagnosis in light of the objective risk estimates the husband is able to recall. Finally, it may be indicative of a style of communication or interaction existing between a highly-educated husband and his wife that influences the woman to remember the objective risk estimates given her in genetic counseling.

Marital history Women in a second or third marriage may be older, yet still want to have a child with their current spouse. Advanced maternal age increases the

risk of having a child with Down syndrome, but there may also be a more pressing desire to have a child (Davies, 1983). Thus, Davies suggested, individuals who have remarried may be more concerned about complications and more reluctant to undergo tests that are perceived to hold a potential for harming the fetus. At the same time, second and third marriages rather than long-standing first marriages may experience more of what Stryker (1959:116) termed "incongruities of definition" and "incongruities of expectations," resulting in personal disorganization. That is, "conflicts or lack of coordination between self concepts and the expectations of others" (Stryker, 1959:116) could cause women to have more difficulty in achieving a definition of the situation and to experience more uncertainty about what their appropriate action should be. This, in turn, could incline them towards the more conservative, passive stance of allowing their pregnancy to continue without taking an action that could potentially create more tension or personal disorganization.

Parity Parity is the term used to describe the number of living children a woman has. Although there has not been uniform consensus on this, much of the research suggests that mothers with several children are less willing to undergo antenatal testing (Marion et al., 1980; Sell et al., 1978). The cause for this finding is not clear, but it

appears that since undergoing amniocentesis is implicitly tied to the possibility of having an abortion, women with several children seem to find this decision difficult. Beckman and Houser (1979) found that women with more children were significantly more likely than those with smaller families or no children to view the rewards of parenthood as being very high in terms of love, fun, companionship, activities, and watching the children grow. Hoffman and Manis (1979) explored reasons for higher fertility desires and found that individuals who wanted larger families felt children gave them a sense of identity and that children would make them a "better" person. Fletcher (1972) characterized the difficulty people experience when considering whether to seek amniocentesis as a struggle between the value of exercising responsible parenthood and the desire to have the child. If these pronatal values and expectations are perceived to be threatened by either the diagnostic procedure itself or by the potential for having an abortion, it can be speculated that multiparous women (those with more than one living child) would rather forego testing than risk injuring or losing an unborn child. Lending support to this analysis, Davies and Doran (1982) found that 59% of the multiparas, as compared with 35% of the nulliparas (women with no living children) considered the prospect of facing an abortion

decision to be very difficult. The primary reasons these mothers gave for their difficulty in reaching a decision about seeking prenatal diagnosis were the desire to have the child and that for them, abortion was morally aversive. Also in Davies and Doran's (1982) sample, 80% of the multiparous women who said they would not be able to abort even if a test proved the fetus to be affected decided against amniocentesis since abortion was not considered an option. Lippman-Hand and Fraser (1979a), Black (1979), Sissine et al. (1981), and Cote (1983) all reported that the overriding cause of reproduction under situations of uncertainty is the intensity of parents' desire for children, leading to decisions that may not necessarily be perceived as rational by an emotionally-uninvolved geneticist, but are in keeping with the individuals' interpretation of their situation.

Insurance In an empirical trial of the health behavior model initially conceptualized by Anderson (1968), Cox and Roghmann (1984) found that having the ability to pay for the cost of prenatal diagnosis through insurance proved to be one of the strongest direct predictors of acceptance of the procedure, accounting for 18% of the variance between acceptance or rejection of amniocentesis. Insurance coverage of amniocentesis also proved to exert a significant indirect effect on discussing genetic testing with both

doctors and with family and friends. This suggests that a very pragmatic consideration in the definition of the situation may in fact influence the action an individual elects to take. Sanders (1982) noted that prohibitive financial costs may affect an individual's decision to seek or refuse medical procedures. For the women whose insurance covered the procedure, their choice between acceptance or rejection of amniocentesis would not be affected by financial constraints.

Significant others Relatively little research has specifically investigated the influence of significant others or reference groups on the acceptance or rejection of prenatal diagnosis. However, from literature exploring health behavior and its relationship to the influence of and interaction with significant others, some derivative conclusions vis-a-vis genetic screening can be inferred.

Suchman (1966) suggested that cultural values and social norms affect health behavior. He viewed health-related behavior--specifically, the use of medical care--as a function of the person's social group and its orientation toward care (scientific versus popular). Similarly, Green (1970) found a persistent relationship between medical prevention or detection and education levels, explaining this in terms of normative influences of the social milieu; people conform to the expectations of

their reference groups and higher status groups have preventive medical norms. Normative thus implies not only permitted, but expected and sanctioned behavior.

Meeker (1980) likewise suggested that to predict the actions an individual will adopt, one must examine social influences. She noted that reference groups, which include extended kin, close personal friends, or members of one's religious and ethnic affiliations, serve as the standard an individual uses for assessing the situation. The influence of these reference groups can help explain changing normative patterns of behavior; once a certain proportion of the population adopts an action, it becomes more viable for others because its consequences are understood. Thus, a decision does not depend only on the interpretation of one individual, but includes such factors as role expectations, influence or conformity processes, and cultural values. As Meeker concluded, communication with others is particularly important in affecting an individual's definition of the situation where outcomes are ambiguous. This would seem to be particularly applicable in the instance of prenatal genetic screening, where diagnosis, prognosis, and outcome are impossible to predict with complete accuracy.

Illustrative of this, Kelly (1986) noted that the results of prenatal testing are expected by some prospective parents to yield unequivocal answers, but the reality falls

short of this expectation. The possible outcomes include a result that is normal, which still doesn't exclude the 3% chance of having a child with significant birth defects not yet detectable with antenatal screening. Test results can be positive for the disorder under question, which suggests decisions on continuation of the pregnancy will be based on the parents' perceptions of the severity of the disorder, the potential for therapy, and their perceived ability to cope with the child's disability. Test results may also establish a diagnosis other than that for which the screening was sought. In some instances, test results are equivocal because the complicated etiology of the disease makes predictions for outcome precarious at best. Finally, in some instances, no results are obtained due to technical problems (e.g., cell culture failure, difficulty in obtaining sufficient amniotic fluid).

Given the uncertainty of the situation and the lack of long-standing normative guidance, findings from earlier process-oriented social research may be applicable. Kirscht (1977) suggested that interpersonal crises (e.g., pregnancy, screening tests, or a physician's advice to seek prenatal diagnosis) threaten interference with ordinary social activities and the perception of a threat to well-being may move the person to act. However, a primary aspect of an individual's evaluation of a health threat involves

comparison with other persons or with the learned standard social groups have imparted to the individual--a normative process. These appraisals of the situation and interpersonal comparisons serve as switches that lead the individual toward or away from a health action. Kirscht opined that most behavior--if not virtually all--is influenced by the practices, beliefs, or attitudes of significant others. In our social spheres there is constant change, particularly with regard to quickly advancing medical techniques. Even such practices as immunization move through the social fabric--requiring changes in beliefs, values, and practices. For genetic screening to be normatively accepted, there would have to be a concomitant shift in sociocultural standards related to sexual matters, contraception, and abortion. Yet, as Kirscht pointed out, norms and attitudes lag behind medical innovations, creating difficulty among those who must respond to and interpret their situations without normative reference group guidance. Modifications in beliefs and behavior can only emanate from changes within social units. Kirscht's delineation of decision-making processes is in keeping with a symbolic interactionistic perspective where people act and are acted upon in an ongoing social exchange. It is also suggestive of the difficulty individuals may encounter if their reference groups have not adopted more liberal perceptions

or normative standards about the advisability of accepting prenatal diagnosis.

Wills (1985) explored the support functions of reference group relationships. He noted that people facing difficult situations search for information and guidance about the nature of and solution to their problems; social networks appear to play an important role in this problem definition. Wills believed significant others or reference groups potentially provide both informational and motivational support. Reference groups can facilitate problem solving by providing information, advice, and guidance. Further, significant others often serve as motivational supports. Wills pointed out that in times of stress, individuals may perceive their difficulty to be overwhelming; a sense of futility may so color their definition of the situation that they give up. Reference group support, however, has the potential for motivating individuals to seek ways of mitigating the difficulty, encouraging them to believe that things will get better, and helping them endure the difficulty by communicating the belief that the problem can be resolved. Similarly, House (1981) noted that reference groups often provide emotional support by bolstering an individual's sense of self by reassuring the person that the problems are not due to personal deficiencies. This may act as a buffering process

against the stigmatizing effect individuals perceive when told that they carry bad genes or are at risk of producing an abnormal child (Goffman, 1963). By expressing concern for and listening to the individual's problems, these significant others can help the person cope with the situation. Similar to Mead's (1934) perspective, Pilisuk and Parks (1986:40) viewed the emotional responses of significant others as most powerful in protection the self-image, allowing the individual to feel "cared for, needed, and worthy of the love of others."

Kessler et al. (1984), Kenen and Schmidt (1978), and Tishler (1981) have all described the sense of failure, shame, guilt, and stigmatization many individuals experience when advised of their at-risk status. Most people expect to be able to produce normal, healthy children. When informed that this may not be the case, a prospective parent is placed in a situation for which societal norms and an individual's sense of self are not prepared. However, Suls and Miller (1977) pointed out that others' opinions are sought in times of uncertainty. Reference groups and significant others, then, may provide the information, motivation, and emotional encouragement to help the individual define the situation and act accordingly. Sanders (1982) noted that if individuals have ambivalent feelings about a behavior, they can help clarify the

situation by comparing their views with the opinions of others. The responses of significant others may assist the individual in deciding whether to adopt the behavior or abandon it. As this relates to medical situations, Campbell (1975) posited reference groups to be helpful in that they may emphasize the negative consequences of a proposed medical intervention. He suggested that this perspective assists the individual in bringing covert fears into the open where they can be examined and potentially resolved.

Findings from studies that explored the influence of others on an individual's health-promoting or seeking behavior, while not directly transferable to genetic screening situations, may suggest some trends. Ninety percent of Davis and Eichorn's (1963) sample reported having asked others' opinions about medical concerns. Heinzelmann and Bagley (1970) found that 80% of their subjects whose spouse was in favor of a treatment regimen, as opposed to only 40% of those whose spouse was neutral or negative, followed the advocated treatment.

Having provided the theoretical relationship between reference groups and the self, relevant studies investigating this relationship in the context of genetic counseling will be reviewed.

Relatives and Friends Achieving a decision about whether to accept or reject amniocentesis extends

beyond the prospective parents involved. Their behavior also reflects their relationships with family, community, and their moral sense of right and wrong (Bringle and Antley, 1980). Meeker (1980) has suggested that in the area of reproduction the most relevant reference groups are probably the family and one's age peers.

The husband of an expectant woman is undoubtedly the most important significant other with whom she will confer about acceptance or rejection of amniocentesis. Indicative of this, the majority of women sampled by Dixson et al. (1981) stated that the decision to have amniocentesis was a joint agreement between husband and wife. However more than one-third of the women had made the actual decision alone; Dixson et al. noted that some of the husbands expressed the view in counseling that the women had to undergo the procedure and potentially an abortion and therefore they felt their wives should make the final decisions. While some women concurred with their husbands, others verbalized feelings of lack of support and burden of responsibility for the test and its outcome. This suggests that a husband's assistance in decision-making can greatly influence not only the decision outcome, but the difficulty with which the choice is made.

According to Kessler (1979:191), "Families are...bound together, usually, by intense and enduring bonds of past

experience, social roles, mutual support, and expectations." It is not surprising that in stress-inducing genetic counseling situations, family ties can be very important. Robinson et al. (1975), for example, suggested that women who feel ambivalent and/or guilty about having amniocentesis and potentially an abortion would be better off discussing these concerns with others, particularly if there are perceived or real conflicts between the mother's views and those of her spouse, relatives, or religion. To explore this further, Adler and Kushnick (1982) interviewed twelve couples who had elected to terminate their pregnancies once the diagnosis of a defective fetus was received. The relatives of the couples in each case had played an extremely important and supportive role during and following the entire period of termination. Not a single family member opposed the decision of the couple.

Ashery (1981) studied communication behaviors between 72 couples having amniocentesis and their relatives and friends. Because amniocentesis is linked with the option of having an abortion, Ashery wanted to investigate whether couples told others they would be having amniocentesis and, among those who did, whom the couples chose to tell. She found that 89% of the couples had confided in close friends, 83% had talked with immediate family members (parents, siblings), 47% with acquaintances, 42% with extended family,

and 6% had talked with no one. Reasons given for not talking to parents included the fear that parents would be unduly worried and the belief that their parents were opposed to abortion. Many of the couples noted that they would have talked to more extended family members or acquaintances if they had been asked, but because the issue wasn't raised they chose not to. Ashery speculated that the higher incidence of telling friends over immediate or extended family members had dual explanations. Given the mobility of American society, perhaps relatives were not in close proximity, or couples may have intuitively turned to friends who were perceived to hold similar attitudes (normative standards) about prenatal testing and the possibility of having a therapeutic abortion.

Ashery (1981) also asked couples to assess the response of the family members and friends they had told. Seventy percent of the couples said those they had talked to approved, 19% of the couples said some approved and others didn't, and 11% had no opinion about the reactions of others. Ashery pointed out that while the majority perceived others' responses to be positive, the couples acknowledged that where they anticipated pressures or negative criticisms from family members or friends, the decision to undergo amniocentesis was simply not discussed. Ashery noted that willingness to discuss amniocentesis

compels a subsequent openness in telling others should an abortion decision be made. Those who told no one, Ashery suggested, would possibly have a more difficult time working through the crisis of waiting for the results of amniocentesis and possibly receiving a positive diagnosis without a network of family and friends upon whom to rely for emotional support. Confirming this viewpoint, Robinson et al. (1984) reported that women with good family or confidant support and/or with a wide range of acquaintances demonstrated significantly lower levels of anxiety while waiting for results from amniocentesis than did those with limited or no support from family, confidants, or acquaintances. However, this study did not query as to whether the women talked to their family members or friends about the amniocentesis itself.

Lubs (1979) examined the opinions of significant others reported by individuals who had been told of their genetic risk. She found that 4% of the couples' relatives advised them to have more children, 33% said the decision was up to the prospective parents themselves, and 19% had suggested that the couple not have children. More than 43% of the couples, however, stated that they had not discussed their at-risk status with anyone. Lubs also asked couples who had discussed their situation with others to assess whom they felt was most influential in their decisions to reproduce or

not. Thirty percent said no one was influential, while nearly 18% of the couples said relatives had helped them decide the best course of action to adopt.

Doctor Given the nature of the problems facing at-risk couples, it is not surprising to find that the referring doctors and/or geneticists can serve as significant reference groups for individuals seeking information and support. Antley and Seidenfeld (1978) suggested that those who enter genetic counseling with a basic understanding of their diagnosis do so to confirm their knowledge and to gain emotional support for their decisions and dilemmas. A study by Dixson et al. (1981) showed that one-fifth of the acceptors but none of the rejectors of amniocentesis cited their physician or genetic counselor as the person who most influenced them to have the procedure.

The role of the doctor in an individual's decision to seek prenatal diagnosis appears to be highly significant. Lippman-Hand and Piper (1981) noted that one of the primary factors influencing the underuse of genetic screening services for women at increased risk for Down syndrome was lack of referral by physicians. In their study they found doctors seldom spontaneously offered prenatal diagnosis; even when tests were requested by pregnant women, Lippman-Hand and Piper discovered that doctors infrequently

referred them to a genetic screening center if the women were less than 38 years of age. This is a particularly relevant finding in light of a recent study by Crandall et al. (1986), who empirically examined the best maternal age at which women should be referred for genetic screening. Reviewing 10,000 amniocentesis cases and outcomes for 1975, 1980, and 1984, Crandall et al. stated that genetic screening should be advocated for women who would be age 34 or older at delivery, and that by the turn of the century, they recommended a maternal age of 30 or higher for genetic diagnosis. They (1986:241) concluded,

> If the maternal age indication is lowered to 30 years and the utilization rate is about 50%, 27% of Down syndrome pregnancies could be identified each year by amniocentesis rather than 18% achieved with the 35-and-older model.

There is evidence that some couples expect a doctor to take a directive stance and are confused at the idea of making their own decisions (Leonard et al., 1972). Lubs (1979) examined the influence medical professionals had on individuals who were aware of their genetic risk. According to the subjects, none of their family doctors advised them to have more children, 22% said the doctor felt the decision was up to the individual, and 14% reported that the doctor had advised against reproduction. Surprisingly, 65% of the couples stated that reproductive decisions were not discussed with their family doctors. Lubs also asked

individuals in her sample to state which medical professional had been most influential; 9% chose their family doctor, 3%, their obstetrician, and 30%, their geneticist. A significant minority (27%) wanted to be advised about family planning and 11% were uncertain, suggesting that directive counseling from physicians may be desired by at least three in ten prospective parents (Lubs, 1979).

Beck et al. (1974) characterized the physician as the most powerful potential advocate of testing, but suggested that the doctor performs poorly in this role. Finley et al. (1977) and Iams et al. (1983) pointed out that prospective parents place confidence in their physician's judgment when there has been a long-standing relationship; thus, the doctor is in a position to offer very influential guidance regarding prenatal diagnosis. Leonard et al. (1972) viewed the physician as the strongest potential motivator both for seeking genetic counseling and using it, but noted that about one-fifth of those coming into genetic counseling had received no information from their family doctors. More recently, Lippman-Hand and Cohen (1980) found obstetricians to be seriously underrefering their patients for prenatal testing. While 82% of the 93 doctors studied had referred at least one eligible patient, almost none had used the prenatal testing services for all appropriate patients;

Lippman-Hand and Cohen concluded that the majority of physicians are underreferers. Bernhardt and Bannerman (1982) similarly found that 47% of the obstetricians in West New York State had never referred a patient for amniocentesis. Weitz (1979) offered some insights as to why this may be. She found that physicians who were Catholic, held religion to be important in their lives, had several children, or were older were less supportive of genetic counseling, amniocentesis, and abortion. When patients firmly requested referral for genetic screening, 56% of the doctors did so. However, 23% of the physicians Weitz studied claimed they received no requests from their patients, and among this group, only 3% had ever referred patients for genetic screening.

Doctors may not be totally at fault, however. Volodkevich and Huether (1981) found that physicians claimed to have counseled 81% of the women who did not utilize but were eligible for amniocentesis about their prenatal risks. Yet only 10 of the 71 women who received the counseling early enough to have undergone genetic screening remembered having discussed their at-risk status with their doctors.

Religion Religion can be perceived as exerting the same normative influence as that of familial or friendship reference groups. Lenski (1963:326), for instance, posited that "socio-religious group membership is

a variable comparable in importance to class." Further, when an individual embraces strong religious convictions, there are often significant others holding similar religious views with whom the person interacts either at church or through friendship liaisons. These reference groups frequently hold similar normative expectations and can reinforce the opinions of the person who must decide whether to undergo amniocentesis, which has distinct implications for seeking an abortion should there be a positive test result.

In addition to the influence of religious friends, religious doctrines provide spiritual norms that may influence the perceptions and behaviors of religious adherents. Wills (1985) noted that some individuals go to church to pray for guidance. The perception that a higher being is assisting the individuals achieve a decision can be as powerful as earthly reference group norms, and thus may exert considerable influence on the choices a person makes.

Interpretation of meaning: risks and attitudes

Risks and odds Throughout its various paradigmatic shifts, genetic counseling's primary objective remained that of education. The effectiveness of counseling was usually assessed in terms of clients' learning of their diagnoses and their ability to recall their chances of producing an affected offspring. The preponderance of

literature about genetic counseling thus focused on risk and diagnosis recall, and used this both as a benchmark to measure genetic counselors' abilities and, more importantly, to evaluate the "rationality" of counselees' decisions. To the extent that prospective parents' behaviors conformed to the interpretation of risk held by the geneticist, counseling was viewed as successful. When their actions appeared to be at variance with a "rational" interpretation of the situation, researchers lamented the failure of genetic education's purposes.

Examples of this focus on client recollection of risks include a study by Emery et al. (1979), which found that 77% of the parents recalled their risk estimates immediately after counseling, 61% remembered at a three-month follow-up, and 53% were able to correctly cite their at-risk odds after a two-year period. At the two-year follow-up, about one fifth of those initially given a low risk (less than 10%) considered it to be high and 20% of those given a high risk (greater than 10%) considered it to be low. Emery et al. speculated that risk interpretation was influenced by outcome burden, as the low risk individuals who thought their risk was high had a poor prognosis. Yet others who considered a high risk to be low included those with diagnoses of Huntington chorea, tuberous sclerosis, and cystic fibrosis (all very burdensome and serious diseases).

To explain this, Emery et al. (1979:1256) suggested these clients revealed an "inability to face realities."

Hsia and Silverberg (1973) reported that while 70% of the counselees recalled that a recurrence risk was given, a large proportion of them left blank the question asking what their exact risk figures were. Godmilow and Hirschhorn (1977) found that high-risk parents tended to underestimate their at-risk status vis-a-vis the geneticist's assessment of their situation. Ives et al. (1973), on the other hand, reported that high-risk groups tended to have more accurate risk figure recall than did those at low risk. Sibinga and Friedman (1971) reported that less than 20% of their patients understood the implications of their genetic diagnosis and that only 48% correctly cited their risk estimates. Similarly, Spiro et al. (1974) noted that only a third of the clients knew their risk odds after one genetic counseling session; after two sessions, two-thirds were able to correctly state their recurrence odds. Reiss and Menashe (1972) reported that only 25% of the counselees could recall their risk rates within a few months after counseling. Similarly, only 26% of the sample investigated by Pearn and Wilson (1973) could state the odds for recurrence of their diagnosis. Oetting and Steele (1982) found no significant differences between counseled and noncounseled couples at risk for Down syndrome in their knowledge of recurrence

risk. Evers-Kiebooms and van den Berghe's (1979) findings, then, were not at all surprising. After reviewing numerous published studies from 1970 to 1977, they concluded that clients making "informed and responsible" decisions did not appear in any way to have been influenced by the risk estimates they were given. In other words, the prospective parents' behavior had not conformed with the expectation of the geneticist who knew their risk ratios.

While studies examining the effectiveness of counseling in terms of client odds recall abilities persist, the majority of researchers are now beginning to focus on the processes prospective parents use to arrive at their decisions. This seems a more practical area to explore, given that genetic variation between individuals makes risk prediction less than certain even for trained geneticists (Fletcher, 1984). Fletcher noted that though disease incidence and carrier frequency may be relatively easy to ascertain, the developmental course a disease takes for each affected child as well as the risks to the mother and fetus associated with prenatal testing are less predictable. Even those parents who accurately recall their risk estimates don't possess fool-proof information on which to base their decisions. Little wonder that research has repeatedly demonstrated that counselees tend to assess their risks in the context of their own definitions of meaning. As Antley

(1979a) pointed out, it is impossible to evaluate prospective parents' behavior without recognizing the many considerations that go into their decision-making processes. Hsia (1979:182) artfully characterized this new perspective that currently helps guide genetic counseling:

> Rational decision making is not a decision judged to be rational by the counselor. Rather, it is a decision made by a counselee who has pondered genetic facts and reproductive options. Hence the final decision may be one that appears unorthodox or illogical to an outside observer, but if a counselee chooses a reproductive option after careful deliberate thought, the decision is rational.

Lippman-Hand and Fraser's (1979a,b) work is particularly salient in this respect. They noted that past research tended to clarify <u>what</u> people facing different risks do, but did not really explain <u>how</u> these family planning decisions were made. They noted that when they began their research, the process of reproductive decision-making under conditions of uncertainty, though substantively important, had not received attention in the literature. There were no empirical data. After extensive qualitative interviews with parents considering whether to try to reproduce given their at-risk status, Lippman-Hand and Fraser concluded that individuals based their actions on their own definitions of the situation, not the geneticist's interpretation of their reproductive risks.

Other researchers have begun to understand that the

counselor's view of the gravity of the risks may not always correspond to that of the client. Callahan (1979), for example, explained the complexity of risk-taking decisions potential parents face given some genetic problem. He (1979:231) stated:

> Many factors have to be weighed simultaneously: known objective probabilities interacting with subjective assessments, available family resources, available society resources, effects on siblings and marital relations, and commitments to values.

Decisions about undergoing prenatal diagnosis will depend only in part on the numerical results of risk estimation. The personal and religious views of the couple will often play a larger role in determining outcomes (Harper, 1983). Levine (1979) concurred. She emphasized that all of life involves risk-taking. Some risks are so trivial they don't even require conscious decision making. People rely on habits, norms, or personal preference to determine their behavior, without taking into account the "probabilities" of making the right or wrong choice. In making highly significant decisions, people more often resort to decision-making patterns they previously used, patterns that rarely take risk odds and ratios into account.

Indicative of this, Laurence and Morris (1981) found that once information about prenatal diagnostic tests became the focus of the genetic counseling encounter, couples appeared not to remember risk figures accurately because on

the whole they no longer perceived them to be relevant. Previous studies by Black (1979), Lubs (1979), Pearn (1979), and Lippman-Hand and Fraser (1979a,b) all have noted that clients interpret their risk for having an affected child in terms of personal and social considerations. Thus, the statistical significance of risk does little to alleviate counselees' reproductive uncertainty. Wertz et al. (1984) found no association between reproductive uncertainty and level of risk. They also found client learning of medical facts, such as diagnosis and risk, did not appreciably reduce clients' conflicts in decision-making. The only piece of medical-genetic information that appeared to reduce uncertainty was the giving of a risk by a counselor in such a way that the client learned that a risk had been given, regardless of whether the client learned this risk correctly and regardless of the level of risk. Wertz et al. concluded that the explanation for counseling's failure to reduce uncertainty is that clients don't base their decisions solely on medical facts, such as risks, but on complex, deeply personal interpretations of these facts. For some clients, a risk of 10% is high, for others, low.

Contrary to their expectations, Sibinga and Friedman (1971) found no correlation between educational achievement level and prospective parents' understanding or distortion of information relating to genetic disease and its etiology.

They believed the incapacity to comprehend might be associated with emotional resistance rather than intellectual ability. It is the parental thinking process rather than intensive efforts of the geneticists that determines what parents understand and what they reinterpret.

Leonard et al. (1972) noted that among 61 families counseled, 44% denied, misunderstood, distorted, or incorrectly interpreted the genetic information. Despite lenient interpretations of tests scores by researchers, only half of the parents had enough understanding of risks to make factually-informed choices. Pearn (1973) pointed out that the way individuals perceive risk may in part be a function of how the odds are quoted. For example, a 1 in 4 risk of abnormality might be interpreted differently than a 3 to 1 chance of having a normal child. He further explained difficulties parents have in remembering risks in terms of personality factors; passive subjects who feel vulnerable to their environment tended to take greater risks, perceiving the situation in a deterministic fashion. Those who feel in control of their environment were more likely to take active measures to deal with their definition of the situation and interpreted odds in a more conventional, and usually conservative, manner.

Shaw (1977) reported that parents tend to distort the

odds given them when they already have an affected child; this stressful situation may make them believe any amount of risk is too great. Shaw also suggested that those who enter genetic counseling with previous beliefs about risks may be less receptive to the odds given them by the geneticist if they differ from those they accepted to be true prior to the new information. Shaw posited that guilt feelings also may modify risk attitudes.

Meeker (1980:25) understood the dilemmas facing parents who are given estimates of their objectives risks, explaining that

> decision making under uncertainty (or worse yet, in cases where we do not know even what outcomes may follow each action) cannot generally be said to have a rational solution.

She pointed out that four items are required to calculate the rational decision in a situation of risk: the actions available, the possible outcomes associated with each action, the probability of each outcome given each action, and the utilities for each outcome. Yet even if these four factors were available, which is not the case in genetic counseling, an individual's interpretation of the situation brings the apparent "rational" decision into question.

Illustrative of personal perceptions that appear to be "irrational," Davies and Doran (1982) found that half of he women who accepted amniocentesis as compared with 88% of

those refusing the test were worried about the procedure. Thirty-nine percent expressed concern about the risk of spontaneous abortion and 36% were afraid the baby could be injured in the process despite fairly consistent findings that such risks are less than 2% for amniocentesis. Among women eligible for genetic testing, three women in ten interviewed by Volodkevich and Huether (1981) stated that the reason they didn't seek amniocentesis was because they didn't feel at increased risk.

Rosenstock (1974) believed individuals take preventive health action when (a) a threat to health is perceived, including the belief that the actor is vulnerable to the condition and that its effects could be severe; (b) a path of action is likely to reduce the threat; and (c) the benefits of acting outweigh the costs. Rosenstock noted, however, that these beliefs are entirely subjective. Genetic susceptibility is a probability concept, but personal views of the meaning of a 1 in 4 chance of a bad outcome will vary. Personal belief in susceptibility may in no way relate to probabilities for aggregates. Lippman-Hand and Fraser (1979b), for example, explored the concept of a "binary" risk. Subjects in their study tended not to view their vulnerability in terms of odds ratios (e.g., a 1:100 chance of having a defective child). Rather, at-risk individuals tended to define their chances as binary: they

either would or would not bear a child with a genetic anomaly. Lippman-Hand and Fraser noted that for certain individuals given a one in one-hundred risk probability, the focus is on the one. They see no reason to believe they might not be that one person in one-hundred whose child is affected. Statistical probabilities have no meaning in the context of this sort of interpretation.

Rosenstock (1974) stated that the interpretation of risk involves a complicated processing of information related to perceptions of meaning and definitions of the situation. For instance, the cost to a woman's self-image of facing the possibility that she can transmit a serious health problem to her child may be too much to bear. According to Emery et al. (1979), this might explain why some high risk individuals elect to become pregnant. They speculated that these couples decided to have children both because they denied the reality of high risk and because they simply did not perceive the problem as serious. Emery et al. further noted that the handicapped seldom perceive their condition to be as severe as do the able-boded, so they are less often deterred by the objective risk estimates of transmitting their disorder to their child.

In the same vein, Antley (1979a) noted that counselees' values in arriving at a decision about genetic testing are major components that will greatly affect the ultimate

choice prospective parents make. Expectant parents generally view their children as self-enhancing extensions of themselves. Rarely do they imagine that their child might have a one-in-twenty risk of being abnormal. To the contrary, the expectation is for a normal child and an ideal family. He posited that counselees block the learning of genetic information because of the meaning the information holds for evaluating themselves as people. That is, their ideal self is out of balance with their perceived behavioral self, causing a great deal of distress in arriving at a decision. Antley speculated that women who reject amniocentesis are still in a stage of denial or dealing with unresolved emotional distress and are therefore unable to accept prenatal genetic diagnosis that would not only confirm their at-risk status but also would hold the potential for making further difficult decisions (to abort or not to abort). Kessler (1979:195), too, noted that individuals facing a major unanticipated stress event frequently experience a "period of denial" in which they attempt to avoid any thoughts or ideas that would remind them of the event or its implications. This denial and avoidance would automatically preclude undergoing genetic diagnosis inasmuch as this would confirm the individual's "spoiled identity." Goffman (1961) described the emotional upheaval and lowered self-concept experienced by those who

live with a stigmatized status. When a prospective mother whose self-concept includes the assumption that she carries normal genes and will produce a healthy, unaffected child learns that her unborn child is potentially at risk, the self will attempt to reestablish a sense of equilibrium and self-worth. Denial of at-risk status may act as a protective device and cause women to refuse prenatal diagnosis since they do not perceive themselves to be at risk of producing an affected child.

McClelland (1980:146) summarized the process as one in which "incorrect information, in the form of inappropriate beliefs about the likelihood of various consequences, may be an important determinant of fertility-related decisions." He noted that with an emphasis on personal beliefs, values, and weights as determinants of fertility decisions, people can be expected to differ in their judgments about which consequences are likely to follow from given behaviors. Even when people are in agreement on the probable consequences of a given behavior, individuals may have very different evaluations of those consequences.

There may also be major individual differences in the decision phase. Some might systematically evaluate many alternative behaviors and then choose the one with the highest overall benefit, while others may adopt a "satisficing" strategy by considering alternative behaviors

sequentially until one is found that seem "good enough" if not necessarily the best.

It thus appears that subjective interpretation of risks and a definition of the situation, not objective risk probabilities, are the most important factors to consider when trying to determine why individuals behave as they do in situations of reproductive uncertainty.

Norms and attitudes Decisions regarding parenthood and childbearing are personal, normative, and value laden. In addition, attitudes towards abortion are germane to the acceptability of prenatal diagnosis for fetal abnormalities (Hsia, 1977). Under threat of having a seriously handicapped child, parents may recognize that an abortion would remove the problem, but they may regard such an action as morally unacceptable and hence prohibitively costly to their self-image and their normative beliefs or attitudes.

Receiving genetic diagnoses influence the way counselees evaluate their situations. The couple who anticipated having a child as an important and good event may, in light of an unsuspected genetic risk, tend to reevaluate the situation in binary terms--either a good or a bad outcome will be realized (Lippman-Hand and Fraser, 1979b). Faced with this reevaluation of what childbearing means, and with the possibility of undergoing prenatal

diagnosis, individuals who previously considered abortion untenable may shift its place in their value hierarchy to being more acceptable than bringing an affected child into the world.

Most prenatal diagnostic centers view the choice to undergo amniocentesis and the abortion decision to be totally separate, but many prospective clients cannot make this distinction (Davies and Doran, 1982). This no doubt explains some of the reasons respondents cite for refusing to undergo genetic screening. Dixson et al. (1981) found that 63% of those rejecting as compared with less than 8% of those accepting amniocentesis felt they definitely could not terminate a pregnancy in which the fetus was determined to be clearly abnormal. Volodkevich and Huether (1981) reported that among women eligible for but not accepting genetic screening, 21% said the reason they refused was opposition to abortion. Nielsen's (1981) study noted a significant relationship between feelings about amniocentesis and attitudes towards abortion. Most subjects expressed the belief that it was a moral, not a religious choice since they, not the church, would be raising the child. However, Nielsen found that Catholics in the sample had significantly higher negative feelings about the procedure than did non-Catholics.

The primary area in which the question of whether to

undergo amniocentesis may be influenced by religious standards is the perceived link between genetic testing and abortion. Research indicates that various denominations systematically vary in their acceptance of abortion (Ebaugh and Haney, 1980; Tedrow and Mahoney, 1979). However, regardless of the denomination, Goettsch (1984) found a significant, uniform opposition to abortion among those who reported religious involvement. This was especially strong for those who regularly attended religious services and who held religion to be very important in their lives.

Applying the importance of religion to research specifically studying amniocentesis decisions, Dixson et al. (1981) noted that among the significant factors affecting those who rejected amniocentesis was the influence of religion. Nearly 60% of the rejectors as compared with only 12% of the acceptors cited their religious beliefs as influencing their decisions about amniocentesis. Black (1979) also found that among couples rejecting amniocentesis, religious teachings against abortion were mentioned. Earlier studies had suggested that individuals belonging to Catholic denominations were less likely to accept amniocentesis, but more recent findings suggest the denomination itself is less important than the attitudes, norms, or moral judgments individuals derive from their religious commitment (Emery et al., 1979; Dixson et al.,

1981; Luker, 1984). Thus, Seals et al. (1985) found that members of small, fundamentalist, or conservative Protestant sects more so than Catholic or Lutheran denominations tended to oppose abortion and were more likely to refuse genetic testing. Among women of the Catholic faith who had undergone amniocentesis, reasons given for accepting the procedure included the view that moral or personal perspectives were more influential than were their denominations' proscriptions against abortion (Nielsen, 1981; Bundey, 1978). Further, Sell et al. (1978) found that familiarity with at-risk status, previous knowledge about genetic screening tests, and learning that one will very likely face the consequences of caring for a seriously defective baby all tended to reduce the resistance to tests among Catholic women. These studies suggest that individual interpretation of religious teachings as applied to their own situations, not the denominational membership per se, may influence individual opposition to abortion and rejection of prenatal screening.

Fletcher (1972) found that the predominant concern of the 25 couples he studied was the dilemma of whether to undergo an abortion. He cast the problem in terms of a conflict between the individual's desire not to bear a genetically-affected child and the fear of being judged harshly against personally-relevant reference group norms

that oppose abortion. Even though amniocentesis requires no prior commitment to abortion, Fletcher noted that prospective parents anguished over their decision given their moral aversion to electively terminating the pregnancy. Finley et al. (1977) and Robinson et al. (1975) likewise found abortion to be a major concern of women considering having amniocentesis. Levine (1979) suggested that an elective abortion for social or psychological reasons is perceived as a matter of personal choice; an abortion for genetic reasons, however, is often accompanied by feelings of guilt, shame, and disappointment that the desired child could not be born.

Focusing on an individual's perceptions is thus very useful in prenatal genetic diagnosis since many social and ethical values are involved (Davies, 1983). Individuals entering genetic counseling may perceive themselves as being caught in the struggle between prolife and antiabortion norms. Fletcher (1979) adroitly captured the essence of these countervailing perspectives regarding abortion:

> The debate in ethics...is polarized between a right-to-life argument that tends to equate genetically indicated abortion with infanticide and a quality-of-life argument that tends towards positive arguments for the morality of abortion and selective euthanasia of the defective neonate (1979:242). ... The strongest feature of the right-to-life argument is the clarity that derives from the objective reality of the fetus. There is human life present...a human life...that deserves equal protection with each and every other human

> life (1979:243). ... The basic strength of the quality-of-life argument rests in its link to the power of authentic human responsibility. In reality, only human beings decide about what is truly human, even if they do so in the power of the belief that humanhood is derived from God, biology, or natural law. If only human beings make these decisions, the argument proceeds, we must not shirk the implications of the responsibility to distinguish personal life from biological life. To turn over any part of our responsibility to decide to forces outside human control is an abdication of the imperative to act in every way to increase the realm of human control and its quality (1979:245).

It appears that individuals deciding their course of action regarding genetic screening may potentially have to weigh the merits and deficits of adhering to their personal reference groups' normative standards. This would entail an interpretation of the meaning of these pro- and antiabortion norms or values within the context of the individuals' own situations. How they mediate their decision given the disparity between these conflicting perspectives may play a major role in determining the choice they adopt and the facility with which they resolve their dilemmas.

Operationalization of the Theoretical Concepts

Given its emphasis on taking an individual's social positions, reference group interactions, and perceptions into account when trying to understand a person's behavior, the use of symbolic interactionism as a guiding theoretical perspective for studying reproductive decisions under

conditions of uncertainty would seem to be quite appropriate. Although not perceived as positing a highly causal theoretical framework, a general model may be derived from the conceptualizations of Mead (1934), Blumer (1969), Kuhn (1964), and Rosenberg (1981) that demonstrates the interrelatedness of self, reference groups, and interpretations of meaning. These processes work together in such a way that the individual defines the situation and acts in concord with this interpretation (Figure 2).

Given substantive guidance from the concepts derived from a review of the literature, this model posits that individuals deciding whether to accept or reject amniocentesis will interpret the meaning and definition of the situation within the context of their social identity. These definitions may not only be influenced by background, status identity factors, but are colored as well by their interpretation of meaning. This suggests that behaviors will frequently be at variance with the perceptions of genetic counselors who have assessed the parents' probabilities of bearing an affected child. At-risk individuals are also influenced by the beliefs, expectations, values, and norms of significant others and reference groups. Thus, individuals facing decisions regarding genetic screening and a potential for undergoing an abortion construct and shape their behaviors and thoughts

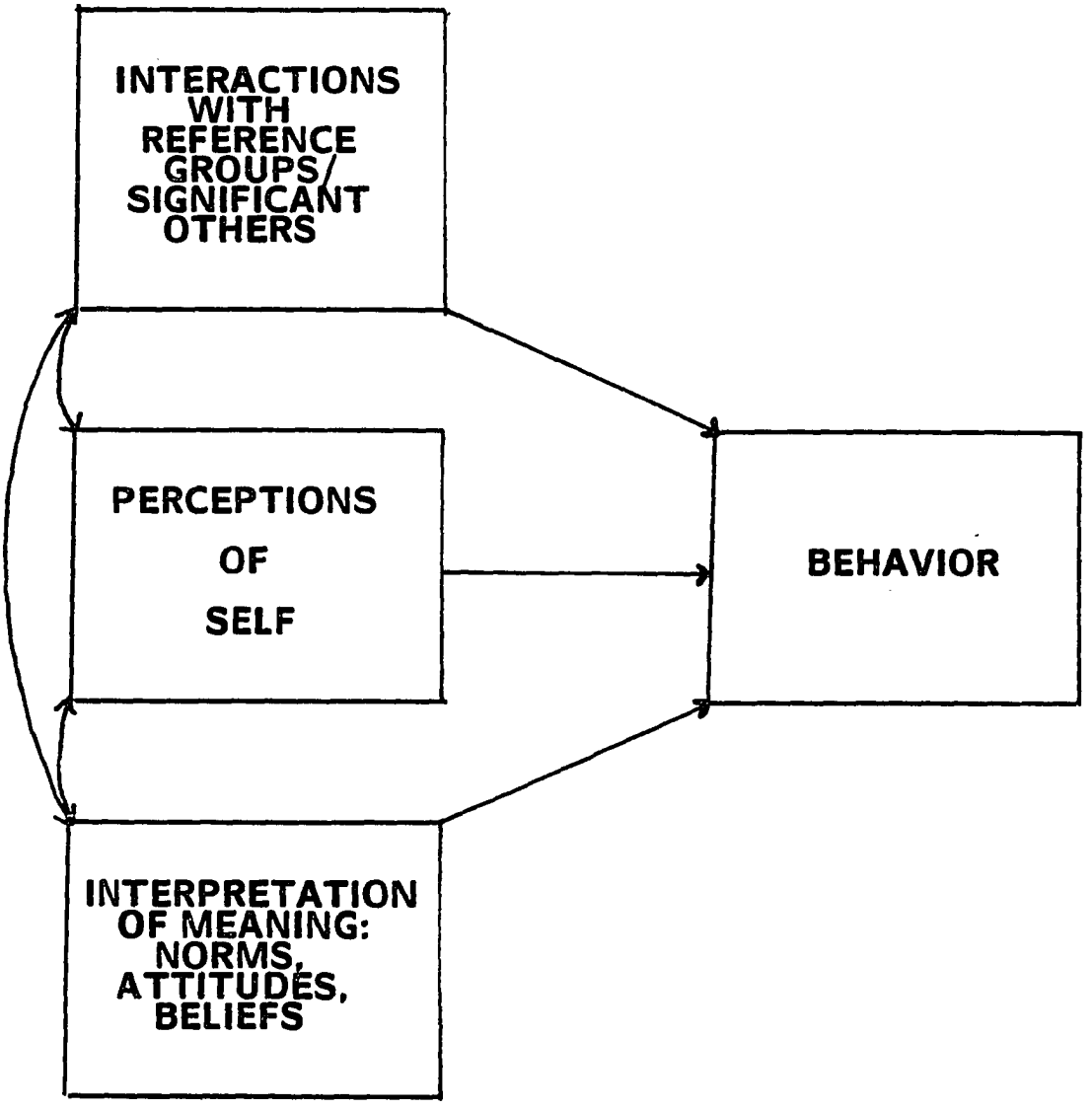

Figure 2. General symbolic interactionism model to predict acceptance or rejection of amniocentesis

in relation to those with whom they interact. Finally, the processes required to arrive at a decision regarding acceptance or rejection of amniocentesis are characterized by the counselees' subjective, not objective, interpretations of the situation. As Turchi (1975:118) summarized it, the decision-making process is not the product of

> the parents' objective situation with respect to income, expenditures on children, membership in particular occupational, education, or religious groups, but the subjective assessment of this situation and their expectations for the future which determine fertility behavior (emphasis in original).

Following the relevant findings of previous research and adhering to the theoretical guidance offered by a symbolic interactionist framework, four general theoretical hypotheses that will direct the current study of acceptance or rejection of amniocentesis can be proposed:

G.H.#1 Respondents whose social identity characteristics engender positive preventive medicine norms, attitudes, and definitions of the situation will be more likely to engage in behaviors such as accepting amniocentesis than will respondents whose social identity characteristics do not promote the development of such norms, attitudes, and definitions of the situation.

G.H.#2 Respondents who interact with significant others and/or reference groups who provide support for and whose normative expectations sanction preventive medicine behaviors will be more likely to engage in behaviors such as accepting amniocentesis than will those who don't interact with or gain support from significant others and whose reference groups are opposed to that behavior.

G.H.#3 Respondents whose norms influence their interpretation of meaning and definition of the situation such that they perceive more beneficial than costly consequences attendant to adopting a preventive medicine behavior will be more likely to engage in such behaviors as accepting amniocentesis than will respondents whose norms influence their interpretation of meaning and definition of the situation such that they perceive more costs than benefits accruing to engaging in a preventive medicine behavior.

G.H.#4 Respondents whose social identity characteristics, reference group and significant other interactions, and interpretations of meaning are all favorably related to adopting a preventive medicine behavior will be more likely to engage in such behaviors as accepting amniocentesis than will those whose social identity characteristics, reference group and significant other interactions, and interpretations of meaning influence them to hold a less favorable perception of a preventative medicine behavior.

In the following chapter the operationalization of concepts and statistical techniques enabling the testing of these four theoretical hypotheses will be explained.

CHAPTER III: METHODS

Sample

The model exploring decision-making processes under conditions of uncertainty will be tested using data collected from 249 female respondents from July, 1981, through June, 1983. During this two-year period, 199 (30.7%) of 649 women accepting and all 29 women refusing amniocentesis who came for genetic counseling to the University of Iowa Hospitals and Clinics Departments of Pediatrics (Genetic Clinic) and Obstetrics/Gynecology for evaluation, diagnosis, and counseling about genetic disease were recruited for the study. Only five women solicited for participation in the project refused.

Another 21 women who rejected amniocentesis were recruited statewide through physicians' offices. These practicing obstetricians and gynecologists were generally cooperative in referring patients to the study. However, there was no way to ascertain the number of women who rejected amniocentesis and likewise refused to participate in the study.

Amniocentesis for genetic diagnosis is primarily advocated for pregnant women 35 years or age or older and for women of any age with family history of risk of having

an infant with Down syndrome or other genetic disease that can be diagnosed prenatally. The incidence of hereditary, familial genetic risk, however, is relatively small, and without extensive familiarity with the case history of the subject, is not very easy to determine. Thus, since all pregnant women age 35 and older are at an increased risk for having a child with trisomy 21, an attempt has been made to evaluate sampling representativeness by comparing respondents of advanced maternal age with older women coming to the University of Iowa Genetic Clinic and with women 35 and older giving birth in the state of Iowa during the approximate period of time over which the study was conducted. From 1981 through 1983, 133,881 women gave birth in the state of Iowa, of whom 5,451 were age 35 and older. Comparisons between the study sample and those potentially eligible because of advanced maternal age to be participants indicate that the study somewhat undersampled women ages 35 and 36, but slightly oversampled women 37 and older (Table 1).

The criteria used to determine whether women were eligible to be recruited for the study included (1) being pregnant, (2) having previously given birth to a child with Down syndrome or another genetic disease currently detectable with prenatal diagnostic procedures, (3) being 35 years of age or older, and/or (4) having family members or

Table 1. Study groups, nonstudy clinic population, and state of Iowa age distribution breakdowns of women giving birth with presumed genetic risk by maternal age 35 and older

	University Hospital Clinic Population							
	Study Group		Nonstudy Group		Women Not Accepting Amniocentesis		Women Giving Birth in Iowa, 1981-1983[a]	
	N	%[b]	N[c]	%[b]	N	%[b]	N	%[b]
Age								
35	29	18.4	77	23.4	4	10.5	1,771	32.5
36	16	10.1	78	23.7	7	18.4	1,133	20.8
37	36	22.8	41	12.5	11	29.0	774	14.2
38	25	15.8	43	13.1	3	7.9	589	10.8
39	19	12.0	36	10.9	4	10.5	414	7.6
40	14	8.9	23	7.0	3	7.9	294	5.4
41 or older	19	12.0	31	9.4	6	15.8	476	8.7
Subtotal, 35 and older	158	79.4	329	78.1	38	76.0	5,451	4.1
Subtotal, 34 and younger	41	20.6	92	21.9	12	24.0	128,430	95.9
Total	199	100.0	421	100.0	50	100.0	133,881	100.0

[a]Compiled from Iowa Department of Health (1983:60; 1984:62; 1985:60).

[b]Percentages of age distributions based on N of 35-and-older subgroups.

[c]Excludes 29 women for whom age data were unavailable.

relatives with a history of genetic disease. Patients coming to the hospital for genetic counseling were interviewed and categorized by a genetic counselor, who determined the eligibility of each patient and recommended them for inclusion in the study. These eligible patients were then approached by a research assistant who thoroughly detailed the study and asked for their consent to become participants. To assure that potential respondents would not be unduly burdened by participation in the project, before the study began it was approved by the appropriate university committee for research involving human subjects.

All the women seen at the University of Iowa Hospital received their genetic counseling from the same physicians and nurse clinician. The 21 women recruited statewide were counseled by their own physicians, and thus there may have been some discrepancy in the content of the counseling these subjects received. However, all 249 subjects were given an extensive information sheet describing the purpose of the study and standardized information about their genetic risk.

After the subjects had consented to be included in the study, arrangements were made to conduct a face-to-face interview. This was generally scheduled during the clinic appointment or soon after the visit in which subjects decided to accept or reject amniocentesis but before the procedure was performed. This was done to avoid obtaining

responses that reflected uncertainty about whether amniocentesis would be accepted. Generally, the questionnaire was administered after the woman had received genetic counseling and had been advised of the procedures related to amniocentesis. The interview was conducted in a special room in the clinic area reserved for the study to ensure privacy and confidentiality. Arrangements were made to interview women rejecting amniocentesis in their home or at a convenient time and place, which would assure that the confidentiality of their responses could be maintained. Those accepting amniocentesis usually were seen between their 15th and 18th week of pregnancy. Rejectors of the procedure generally were interviewed between their 18th and 22nd week of pregnancy, after the time in which amniocentesis could be performed had passed. This was done for several reasons. First, because of difficulties in coordinating schedules of respondents and interviewers subsequent to the women's counseling session (among those who attended the Genetic Clinic) and their refusal of amniocentesis, this time period was often the earliest the interview in the respondent's home could be conducted. In addition, this timing was necessary to assure that the respondents would not alter their decisions about amniocentesis subsequent to the interview. And finally, a later interviewing period was undertaken in the hope that

questions would not again raise anxiety levels and engender further uncertainty about whether the diagnostic test should have been sought.

Two research assistants with master's degrees, one in sociology and the other in preventive medicine, each with three or more years of experience in conducting face-to-face interviews, administered the questionnaire. Subjects were given a copy of the research instrument and were asked to follow along as the research assistant read each question aloud. If the subjects understood the question, they were requested to choose the appropriate answer from a response card listing all the possible categories from which they could choose. If the subjects could not grasp what was being asked, the interviewer read the question once again without rewording it, thereby avoiding response bias due to rephrasing or restructuring of the question. Subjects were encouraged to select the response that most closely approximated their understanding of the question. Participants could refuse to answer any question and were informed that they could withdraw from the study at any time.

Before the study began, the ease of administration of the instrument, the wording of the questions, and subjects' comprehension of the questions were evaluated in a pilot study. The research questionnaire was administered to 30

female volunteers, age 35 or older, who were recruited from patients attending the obstetrics and gynecology clinics for nongenetic reasons. They were encouraged to point out any difficulties they experienced in understanding the wording of the questions; they were also asked to indicate which, if any, questions caused embarrassment or distress. The research assistants then prompted volunteers to suggest ways in which the interview instrument could be improved. Difficulties in comprehension or with the content of the questionnaire were corrected during this stage.

Basic demographic information was collected on all study participants. These background variables have been analyzed to determine whether there was any systematic distribution bias introduced due to the sampling procedure. Ages ranged from 19 to 47, with a mean of 35.9 years; there was no significant difference in the mean age of acceptors or rejectors (t=.258, NS) (Table 2). The majority of respondents were married (82.0% of the rejectors, 94.0% of the acceptors, X^2=7.4, p=.01); one woman in each group was widowed, five in each divorced, three rejectors and one acceptor were separated, and five acceptors were single. Acceptors reported significantly higher incomes than did rejectors (X^2=11.1, p=.01); 62.3% of the acceptors as compared with 42.0% of the rejectors had incomes of $25,000 or more. About one in five rejectors compared with one in

Table 2. Demographics of acceptors/rejectors of amniocentesis

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
	199	100.0	50	100.0	249	100.0
Age						
19-24	4	2.0	2	4.0	6	2.4
25-29	18	9.0	7	14.0	25	10.0
30-34	19	9.6	3	6.0	22	8.8
35-39	125	62.8	29	58.0	154	61.9
40 or older	33	16.6	9	18.0	42	16.9
Mean	36.0		35.7		35.9	
S.D.	4.5		5.3		4.7	
Marital status						
Married	187	94.0	41	82.0	228	91.6
Widowed	1	0.5	1	2.0	2	0.8
Divorced	5	2.5	5	10.0	10	4.0
Separated	1	0.5	3	6.0	4	1.6
Single	5	2.5	0	0.0	5	2.0
Income						
Up to $10,000	11	5.5	9	18.0	20	8.0
$10,000-$24,000	61	30.7	18	36.0	79	31.7
$25,000 or More	124	62.3	21	42.0	145	58.3
No Response	3	1.5	2	4.0	5	2.0
Religion						
Lutheran	51	25.6	13	26.0	64	25.7
Catholic	30	15.1	15	30.0	45	18.1
Methodist	33	16.6	4	8.0	37	14.9
Baptist	12	6.0	2	4.0	14	5.6
Presbyterian	9	4.5	1	2.0	10	4.0
Nondenominational Christian	8	4.0	4	8.0	12	4.8
Small Christian Sects	27	13.6	6	12.0	33	13.3
Non-Protestant	4	2.0	1	2.0	5	2.0
Other	2	1.0	0	0.0	2	0.8
No Religion	22	11.1	4	8.0	26	10.4
No Response	1	0.5	0	0.0	1	0.4
Reason for Referral						
Advanced Age	148	74.4	38	76.0	186	74.7
Family History	23	11.6	8	16.0	31	12.5
Combination	18	9.0	1	2.0	19	7.6
Other	10	5.0	3	6.0	13	5.2

ten acceptors had incomes of less than $10,000 a year. There was a significantly higher proportion of Catholics among the rejectors than the acceptors (X^2=5.9, p=.05) although these represented just 30.0% and 15.1% of their respective groups. The majority of subjects gave their reason for referral to the genetic counseling clinic as advanced maternal age (76.0% of rejectors, 74.3% of acceptors, X^2=8.3, NS). According to the data (Table 1), actually a larger proportion of the acceptors were age 35 or older (79.4%), but the referring doctors may have stressed another reason when suggesting that they seek genetic counseling, or these women may have given answers that placed them in the "other" category.

Measures

Dependent variable

Acceptance or rejection of amniocentesis Subjects were categorized as to their rejection (reject=0, N=50) or acceptance (accept=1, N=199) of the prenatal diagnostic procedure.

Independent variables

Social identity elements: the self Five measures were used to assess each subject's social identity. The women's and their husband's highest educational attainment levels were ascertained by asking, "How many years of school

did you [your husband/child's father] complete and get credit for?" (range 7-20 years for the women, mean=14.3, s.d.=2.8; range 5-20 years for the husbands/babies' fathers, mean=14.5, s.d.=3.0). Parity was assessed by two questions: "How many children have you ever had?" and "How many of your children are now living?" The actual number of living children given was recorded (range=0-7, mean=1.8, s.d.=1.4). Previous or current divorce status was measured with the question, "Have you ever been divorced or legally separated?" (yes, no). Insurance coverage for the amniocentesis procedure was measured by asking, "Does your policy cover such tests as amniocentesis?" (no, yes).

Reference groups/significant others To assess the influence of and interaction with reference groups and significant others, subjects were asked to respond to several questions. "Did your husband think you should have the amniocentesis test?" (no, up to the woman, yes). "How much emotional support are you receiving from your husband [child's father] for your decision about the amniocentesis test?" "How much emotional support are you receiving from your parents for your decision about the amniocentesis test?" "How much emotional support are you receiving from your friends and neighbors for your decision about the amniocentesis test?" (not discussed, no support, very weak, moderately weak, moderately strong, very strong support).

A subsample of the respondents was asked two questions relating to the support the women received from their doctors. These questions were added to the questionnaire after information volunteered by respondents indicated that their doctors' opinions and support might be important factors to consider when attempting the determine why the women accepted or rejected amniocentesis. A total of 158 respondents were asked, "Did your doctor think you should have the amniocentesis test?" (no, up to the woman, yes), and 148 were asked to respond to the question, "How much emotional support are you receiving from your doctor for your decision about the amniocentesis test?" (not discussed, no support, very weak, moderately weak, moderately strong, very strong support). These variables will be entered into analyses in addition to those using the entire sample.

The importance of religion, which might provide reference group support and norms in the lives of the respondents, was assessed by the question, "How strong a [stated denomination preference] are you?" (very strong, somewhat strong, no opinion, not very strong, not strong at all, no religious preference/no religion).

Interpretations of meaning To measure respondents' definitions of the situation and interpretation of meaning, four questions relating to perceptions of risk were asked. Respondents' estimations of the probability that

amniocentesis would accurately identify all patients who have the condition in question if test results were positive were assessed by asking, "In your opinion, what are the chances of correctly identifying a child with Down syndrome by use of amniocentesis?" (very low chance, moderately low chance, 50-50 chance, moderately high chance, very high chance). To evaluate respondents' subjective interpretations of their susceptibility to having a genetically-affected child, they were asked, "What would you estimate is the chance or risk of your having a child with Down syndrome, if you carried this pregnancy to term?" (very low chance, moderately low chance, 50-50 chance, moderately high chance, very high chance). Respondents' perceptions of risks attendant to the procedure itself were measured by asking, "What do you think are your chances of developing complications from the amniocentesis test?" (very high chance, moderately high chance, 50-50 chance, moderately low chance, very low chance). Finally, women's perceived willingness to accept chances of complications from the test were assessed by the question: "How safe a procedure would amniocentesis have to be for you to accept it? Give me the number of the response <u>below</u> which you would <u>not</u> accept the test" (any chance of complications, 1 in 1,000, 1 in 500, 1 in 100, 5 in 100, 20 in 100, 50 in 100, 70 in 100, 90 in 100).

Three questions were used to measure abortion/ antiabortion attitudes. Respondents' feelings about the sanctity of life were assessed by asking, "How strongly do you agree with the statement that 'Life should be preserved under all circumstances all the time'?" (strongly agree, agree, no opinion, disagree, strongly disagree). To measure subjects' attitudes about their approval of situation-specific abortion, they were asked, "Would you approve the use of abortion as a means of avoiding the birth of children with birth defects?" (strongly disapprove, disapprove, no opinion, approve, strongly approve). Finally, the impact religious teachings exerted on their norms and values relating to abortion was ascertained by asking respondents, "How strongly based on religious teachings and beliefs are your feelings about abortion?" (very strongly, strongly, moderately, not at all strongly, my church doesn't take a stance on abortion, I have no religious affiliation).

Operationalization of Hypotheses

Given concrete measures, a more detailed model can be developed (Figure 3) and the theoretical hypotheses can be operationalized into empirically researchable predictions.

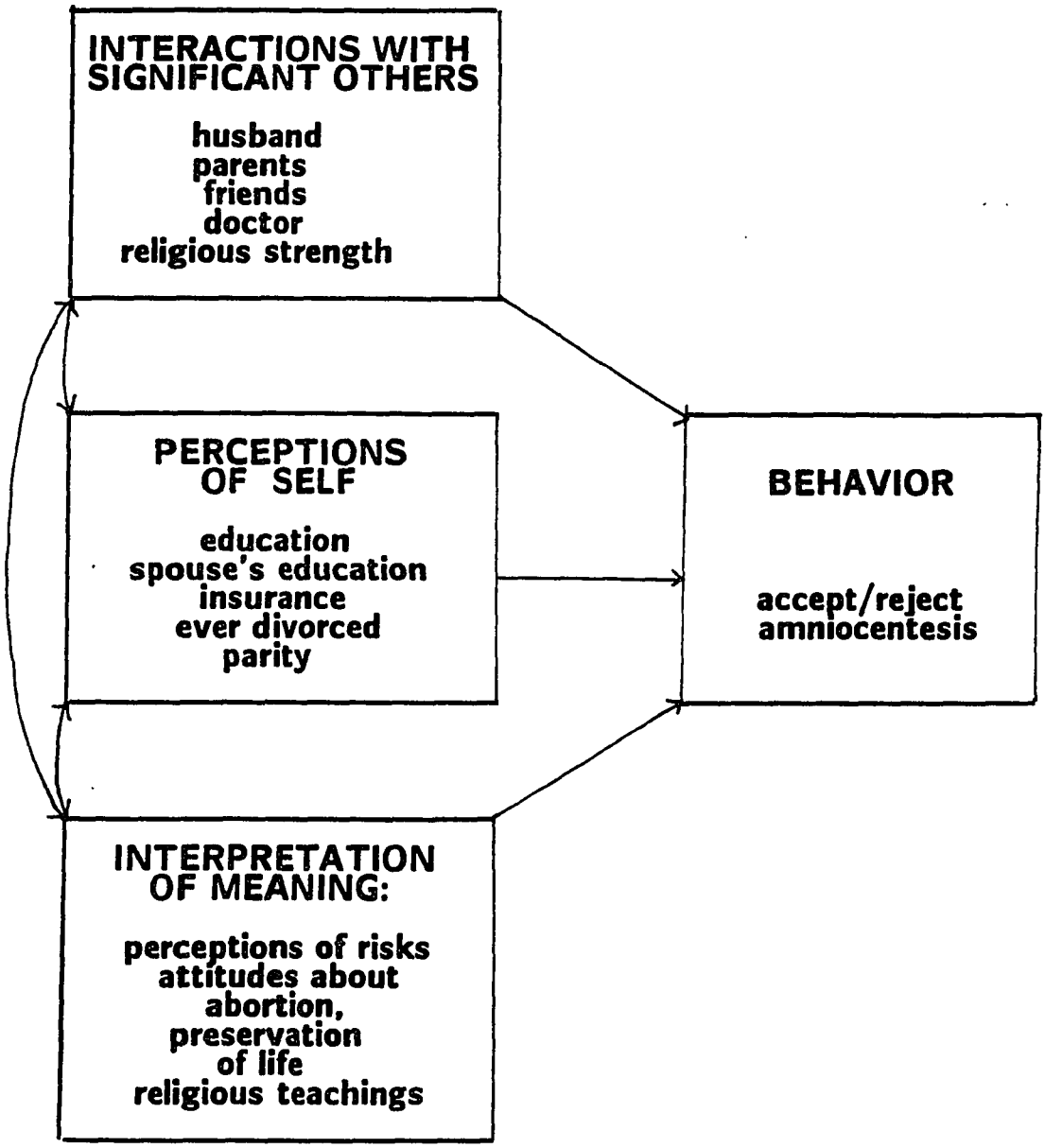

Figure 3. Detailed symbolic interactionism model to predict acceptance or rejection of amniocentesis

E.H.#1 Respondents with fewer children, with higher education for wife and spouse, in first rather than subsequent marriages, and and who are covered by insurance that pays for the procedure will more likely accept than reject amniocentesis.

E.H.#2 Respondents whose husbands and doctors think they should have the procedure, whose husband, parents, friends and neighbors, and doctor provide emotional support for their decision about the procedure, and whose religious strength is not very strong will be more likely to accept than reject amniocentesis.

E.H.#3 Respondents who perceive the accuracy of amniocentesis and their chances of having a Down syndrome child as high; who believe their risks of developing complications from the test as low, yet are willing to accept lower margins of test safety; who do not strongly agree that life should be preserved under all circumstances; who approve of abortions to prevent birth defects; and whose religious teachings have not strongly influenced them in their attitudes about abortion will more likely accept than reject amniocentesis.

E.H.#4 Respondents who have the salient social identity elements, who have significant others who think they should accept the test and whose reference groups lend emotional support, who perceive their risks of bearing a genetically-affect child as high but the risks attendant to the procedure as low, and whose religious teachings and attitudes allow abortion for genetic defects will be more likely to accept than reject amniocentesis.

Statistical Techniques

Relationships among the variables in the model will be assessed by logistic regression statistical procedures. To examine the bivariate relationship between each independent variable and the dependent variable, simple logistic regression will be performed. Subsequently, multiple logistic regressions will be run on independent variables grouped in each of the three conceptual categories (social identity elements, reference group, and interpretation of meaning) to explore their relationships with the dependent variable. Independent variables found to be significantly related to acceptance or rejection of amniocentesis in subgroup analyses then will be entered into a final logistic regression run. To facilitate interpretation of the meaning of the results, odds ratios of each significant variable will be calculated, as will a 95% confidence interval. Findings from these statistical analyses will be delineated in Chapter Four.

CHAPTER IV: RESULTS

The Variables

The 249 respondents were a fairly highly educated group. More than half the acceptors and nearly four in ten of the rejectors had schooling beyond twelfth grade (Table 3). Their spouses had achieved similar levels of education, with acceptors' husbands having a mean of 14.6 years and rejectors' husbands, an average of 13.8 years of schooling.

More than one-third of the respondents had been or currently were divorced, although this was true for about 10.0% more of the rejectors than acceptors (42.0% versus 32.2%). The number of living children respondents reported ranged from none (18.5%) to seven (0.8%), with a mean of 1.7 children per respondent. Rejectors had larger families, with 36.0%, as compared with 21.1% of the acceptors, having three or more children. More of the acceptors (74.4%) than rejectors (44.0%) had insurance covering the amniocentesis procedure.

The majority of women (83.1%) reported that their husbands or the babies' fathers expressed a definite opinion about whether they should have amniocentesis, while 15.7% of the respondents stated that the husband (child's father) had left it up to the woman to decide. Among women accepting

Table 3. Coding[a] of and responses to questions measuring social identity elements, by acceptors and rejectors of amniocentesis

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
Years of women's education[b]						
7-11 years (0)	9	4.5	8	16.0	17	6.8
12 years (1)	75	37.7	22	44.0	97	39.0
13-16 years (2)	61	30.7	11	22.0	72	28.9
17-20 years (3)	54	27.1	9	18.0	63	25.3
Mean	14.5		13.4		14.3	
S.D.	2.7		3.1		2.8	
Years of spouses' education[b]						
5-11 years (0)	13	6.5	4	8.0	17	6.8
12 years (1)	58	29.2	21	42.0	79	31.7
13-16 years (2)	78	39.2	14	28.0	92	37.0
17-20 years (3)	49	24.6	10	20.0	59	23.7
No response	1	0.5	1	2.0	2	0.8
Mean	14.6		13.8		14.5	
S.D.	3.0		2.9		3.0	
Ever divorced						
Yes (0)	64	32.2	21	42.0	85	34.1
No (1)	135	67.8	29	58.0	164	65.9

[a]Values were recoded to reflect hypothesized relationtionships with the dependent variable, rejectors, (0) and and acceptors, (1).

[b]To facilitate comparisons by somewhat conventional groupings of years of education, the range of years reported has been collapsed into four categories.

Table 3. (continued)

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
Parity						
No children (3)	39	19.6	7	14.0	46	18.5
One child (2)	58	29.1	13	26.0	71	28.5
Two children (1)	60	30.2	12	24.0	72	28.9
Three children (0)	21	10.6	10	20.0	31	12.5
Four children (0)[c]	13	6.5	5	10.0	18	7.2
Five children (0)	4	2.0	0	0.0	4	1.6
Six children (0)	3	1.5	2	4.0	5	2.0
Seven children (0)	1	0.5	1	2.0	2	0.8
Mean	1.7		2.1		1.8	
S.D.	1.4		1.6		1.4	
Insurance for amniocentesis						
No (0)	51	25.6	28	56.0	79	31.7
Yes (1)	148	74.4	22	44.0	170	68.3

[c]The same coding number reported for more than one category indicates how the values were collapsed for logistic regression analysis.

amniocentesis, 84.4% said that their husbands thought their wives should have amniocentesis; in contrast, only 12.0% of the rejectors claimed their husbands thought this (Table 4). More than two-thirds of the respondents (67.5%) stated that their husbands very strongly supported their decisions regarding the test and another 23.7% said that their spouses had given them moderately strong support for their decisions. There was relatively little difference between acceptors and rejectors on this measure.

Less than one-third of the women reported receiving very strong support from their parents for their decisions about amniocentesis (31.7% of the acceptors; 30.0% of the rejectors). However, 44.0% of the rejectors and 32.7% of the acceptors said they hadn't discussed their decision with their parents. The women's reticence about discussing their decision was even more evident in their response to the question about the amount of support they received from friends and neighbors; 54.0% of the rejectors and 35.2% of the acceptors claimed not to have discussed their decisions with these reference groups. One-fourth of the acceptors, compared with one-eighth of the rejectors, reported receiving very strong support for their decisions from friends and neighbors.

Among the 158 women who were queried about the amount of support they were receiving from their doctors for their

Table 4. Coding of and responses to questions measuring influence of and support from reference groups and significant others, by acceptors and rejectors of amniocentesis

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
Husband [child's father] thinks woman should have amniocentesis						
No (0)	3	1.5	30	60.0	33	13.2
Up to the woman (1)	27	13.6	12	24.0	39	15.7
Yes (2)	168	84.4	6	12.0	174	69.9
No response	1	0.5	2	4.0	3	1.2
Amount of support from husband [child's father] for woman's decision about amniocentesis						
Not discussed (0)	1	0.5	0	0.0	1	0.4
None (0)	1	0.5	2	4.0	3	1.2
Very weak (0)	3	1.5	3	6.0	6	2.4
Moderately weak (0)	7	3.5	2	4.0	9	3.6
Moderately strong (1)	47	23.6	12	24.0	59	23.7
Very strong (2)	138	69.4	30	60.0	168	67.5
No response	2	1.0	1	2.0	3	1.2
Amount of support from parents for woman's decision about amniocentesis						
Not discussed (0)	65	32.7	22	44.0	87	35.0
None (1)	4	2.0	3	6.0	7	2.8
Very weak (1)	6	3.0	3	6.0	9	3.6
Moderately weak (1)	12	6.0	1	2.0	13	5.2
Moderately strong (2)	49	24.6	5	10.0	54	21.7
Very strong (3)	63	31.7	15	30.0	78	31.3
No response	0	0.0	1	2.0	1	0.4

Table 4. (continued)

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
Amount of support from friends and neighbors for woman's decision about amniocentesis						
Not discussed (0)	70	35.2	27	54.0	97	39.0
None (1)	6	3.0	2	4.0	8	3.2
Very weak (1)	2	1.0	1	2.0	3	1.2
Moderately weak (1)	12	6.0	3	6.0	15	6.0
Moderately strong (2)	58	29.2	11	22.0	69	27.7
Very strong (3)	50	25.1	6	12.0	56	22.5
No response	1	0.5	0	0.0	1	0.4
Amount of support from doctor for woman's decision about amniocentesis						
Not discussed (0)	2	1.0	4	8.0	6	2.4
None (0)	4	2.0	9	18.0	13	5.2
Very weak (0)	3	1.5	1	2.0	4	1.6
Moderately weak (0)	5	2.5	2	4.0	7	2.8
Moderately strong (0)	27	13.6	9	18.0	36	14.5
Very strong (1)	77	38.7	5	10.7	82	32.9
No response/not asked	81	40.7	20	40.0	101	40.6
Doctor thinks woman should have amniocentesis						
No (0)	5	2.5	3	6.0	8	3.2
Up to the woman (1)	32	16.1	28	56.0	60	24.1
Yes (2)	85	42.7	5	5.6	90	36.1
No response/not asked	77	38.7	14	28.0	91	36.6
Religious strength						
Very strong (0)	53	26.6	21	42.0	74	29.7
Strong (1)	70	35.2	14	16.7	84	33.8
Somewhat strong (2)	15	7.5	4	21.1	19	7.6
Not very strong (3)	36	18.1	7	16.3	43	17.3
Not strong at all (4)	5	2.5	0	0.0	5	2.0
No religion (5)	20	10.1	4	8.0	24	9.6

decisions about amniocentesis, 65.3% of the acceptors as compared with 16.7% of the rejectors reported receiving very strong support. Eighty-five of the 122 acceptors as compared with five of the 30 rejectors who were asked stated that their doctor thought they should have the test. A large majority of rejectors (77.8% of the 36 asked) reported that their doctors had left the decision up to them; in comparison, 26.2% of the acceptors claimed their doctors had told them to decide themselves.

Relatively few respondents reported having religious beliefs that were not at all strong (2.0%) or stated no religious preference (9.6%). However, the rejectors were considerably more likely than were acceptors to view their religious preference as very strong; 42.0% of the acceptors as compared with 26.6% percent of the rejectors were in this category.

The majority of acceptors (77.4%) as compared with 46.0% of the rejectors perceived the likelihood that amniocentesis would be able to detect a fetus with Down syndrome as very high (Table 5). Twenty percent of the rejectors but only 3.5% of the acceptors thought the test would have a 50-50 or smaller chance of correctly identifying a child with Down syndrome.

Three women (all acceptors) felt the risks of having a Down syndrome child were very high. The majority of both

Table 5. Coding of and responses to questions measuring interpretation of meaning of risks and attitudes about abortion, by acceptors and rejectors of amniocentesis

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
Women's perceptions of test's accuracy in detecting presence of Down syndrome fetus						
Very low (0)	0	0.0	2	4.0	2	0.8
Moderately low (0)	0	0.0	1	2.0	1	0.4
50-50 chance (0)	7	3.5	7	14.0	14	5.6
Moderately high (1)	37	18.6	16	32.0	53	21.3
Very high (2)	154	77.4	23	46.0	177	71.1
No response	1	0.5	1	2.0	2	0.8
Women's perceptions of odds of having a child with Down syndrome						
Very low (0)	76	38.2	27	54.0	103	41.4
Moderately low (1)	72	36.2	17	34.0	89	35.7
50-50 chance (2)	32	16.1	5	10.0	37	14.9
Moderately high (3)	16	8.0	0	0.0	16	6.4
Very high (3)	3	1.5	0	0.0	3	1.2
No response	0	0.0	1	2.0	1	0.4
Women's perceptions of risk of complications with amniocentesis						
Very low (3)	75	37.7	10	20.0	85	34.1
Moderately low (2)	90	45.2	20	40.0	110	44.2
50-50 chance (1)	28	14.1	11	22.0	39	15.7
Moderately high (0)	4	2.0	6	12.0	10	4.0
Very high	0	0.0	0	0.0	0	0.0
No response	2	1.0	3	6.0	5	2.0

Table 5. (continued)

	Acceptors		Rejectors		Total	
	N	%	N	%	N	%
Chances of complications from amniocentesis woman is willing to accept						
Accept no risks (0)	0	0.0	26	52.0	26	10.4
1 chance in 1000 (1)	17	8.5	7	14.0	24	9.7
1 chance in 500 (2)	51	25.6	8	16.0	59	23.7
1 chance in 100 (2)	40	20.1	4	8.0	44	17.7
5 chances in 100 (3)	41	20.6	3	6.0	44	17.7
20 chances in 100 (4)	24	12.1	2	4.0	26	10.4
50 chances in 100 (4)	17	8.6	0	0.0	17	6.8
70 chances in 100 (4)	4	2.0	0	0.0	4	1.6
90 chances in 100 (4)	2	1.0	0	0.0	2	0.8
No response	3	1.5	0	0.0	3	1.2
Agree that life should be preserved at all times						
Strongly Agree (0)	18	9.1	13	26.0	31	12.4
Agree (1)	20	10.1	16	32.0	36	14.5
No opinion (2)	16	8.0	3	6.0	19	7.6
Disagree (3)	92	46.2	14	28.0	106	42.6
Strongly disagree (4)	53	26.6	4	8.0	57	22.9
Approval of abortion to avoid birth defects						
Strongly disapprove (0)	5	2.5	9	18.0	14	5.6
Disapprove (1)	11	5.5	11	22.0	22	8.8
No opinion (2)	18	9.1	10	20.0	28	11.2
Approve (3)	75	37.7	15	30.0	90	36.2
Strongly approve (4)	89	44.7	5	10.0	94	37.8
No response	1	0.5	0	0.0	1	0.4
Strength to which feelings about abortion are based on religious teachings						
Very strongly (0)	21	10.6	16	32.0	37	14.9
Strongly (1)	22	11.1	12	24.0	34	13.7
Moderately strongly (2)	42	21.1	8	16.0	50	20.1
Not strongly at all (3)	76	38.2	8	16.0	84	33.7
Church takes no stance on abortion (3)	16	8.0	2	4.0	18	7.2
No religion (3)	20	10.0	4	8.0	24	9.6
No response	2	1.0	0	0.0	2	0.8

groups (74.4%, acceptors; 88.0%, rejectors) perceived their chances of having a child with Down syndrome as moderately or very low.

None of the respondents believed there would be a very high risk of complications associated with amniocentesis, although 34.0% of the rejectors as compared with 16.1% of the acceptors thought there could be a 50-50 or moderately high risk of complications with the procedure. Nearly two in five acceptors as opposed to one in five rejectors perceived risks associated with the test as being very low.

The chances of complications the respondents would be willing to accept in order to undergo amniocentesis ranged widely over nine risk categories. However, more than half (52.0%) of the rejectors (but none of the acceptors) stated that they would not undergo the procedure unless there were no chances of complications. At the other extreme, 17 acceptors stated that they would be willing to accept a 50.0% complication risk, 4, a 70.0% risk, and 2, a 90.0% risk. None of the rejectors was willing to accept these high levels of risk of complications with amniocentesis.

Fifty-eight percent of the rejectors as compared with 19.2% of the acceptors agreed or strongly agreed that life should be preserved at all times under all circumstances. Few respondents (7.6%) expressed no opinion. More than seven in ten acceptors and not quite four in ten rejectors

disagreed or strongly disagreed with this statement used to probe their normative beliefs about the sanctity of life.

A fairly large minority (9.1% of the acceptors, 20.0% of the rejectors) expressed no opinion about approval for abortion to avoid birth defects. Forty percent of the rejectors disapproved or strongly disapproved of abortions to avoid birth defects, while 82.4% of the acceptors approved or strongly approved of abortion under such circumstances.

Religious teachings very strongly or strongly influenced 56.0% of the rejectors' but only 21.7% of the acceptors' feelings about abortion. Nearly two in five acceptors as compared with one in six rejectors stated that religious teachings did not influence their feelings about abortion at all strongly.

Logistic Regression

To examine various components of the four hypotheses delineated in Chapter 3, the bivariate relationship of each of the independent variables ($X_1,\ldots,X_k$) to the dependent variable (Y) will be tested for statistical significance using logistic regression. Logistic regression is somewhat similar to ordinary regression, where Y's dependence on X is typically studied by means of the following equation:

$$Y = a + beta_1 X_1 \qquad (1)$$

The foundation for using the logistic rather than the ordinary regression is complex (Hanushek and Jackson, 1977), but the most obvious reason deals with the assumption in ordinary regression that the dependent variable is continuous, which is not the case in the present study. In instances where the dependent variable is binary (Y=0 or Y=1), equation (1) in essence postulates that the probability of observing a particular outcome is a linear function of the independent (X) variable. As long as the probabilities fall close to 0.50 for all values of each of the independent variables, the assumption of linearity may be reasonable and results derived from ordinary regression would be quite similar to that obtained from logistic regression (Goodman, 1976; Fleiss et al., 1986). However, when studying relatively rare events (with probabilities of less than 0.25) or relatively prevalent occurrences (probabilities greater than 0.75), analyses using traditional regression would produce inaccurate results, such as predicted probabilities less than 0 or greater than 1. Thus, it is essential to use a procedure that does not produce such distortions of the results. The method of analysis adopted in this study is logistic regression.

To achieve a linear relationship between X and Y, the Y variable must be converted to a ratio between one outcome and the other. Here, instead of considering the original

dependent variable Y (0=reject, 1=accept) as a linear function of the independent variable, the log odds of the probabilities of those who accepted (p) and those who rejected (1-p) amniocentesis becomes the dependent variable. That is, the dependent variable is expressed in terms of log odds, or the log of the ratio of probabilities for acceptance or rejection:

$$\log[p/(1-p)]$$

Given this conceptualization, as long as the dependent variable is in a log odds form, the logistic equation becomes equivalent to that of an ordinary regression equation:

$$\log[p/1-p] = a + \text{beta}_1 X_1 \qquad (2)$$

This formula has the appeal of offering a common-sense and somewhat more familiar interpretation of the function of logistic regression. However, finding the probability of acceptance, or p(Y=1), is the actual objective of the present study. To derive this, the dependent variable must be expressed in terms of a logistic function of the probability of acceptance. Using the exponential (exp) equation for a binary model, the regression equation can be rewritten to express the dependent variable as the probability of acceptance (p):

$$p = 1/[1 + \exp(-a - \text{beta}_1 X_1)] \qquad (3)$$

Although the log form as expressed in formula (3) is

more complex than ordinary regression, it has at least one important advantage over it. The predicted probability will remain within legitimate bounds--between 0 and 1 (i.e., zero probability or the probability of one), while in ordinary regression, the predicted probability could go beyond these boundaries. Amounts greater than 1 and less than zero do not exist in probabilities. Logistic regression analysis, although a variant of ordinary regression, thus allows for the study of quantitative as well as categorical independent variables without having to contend with the possibility that skewed data will produce unreasonable results.

Given these properties, bivariate logistic regression can be employed to test the importance of an independent variable in relationship to the dependent variable. The regression coefficient beta represents the impact of the independent variable on the dependent variable; it is used to determine if the influence of an X variable is statistically significant and, if so, whether the relationship between X and Y is in the posited direction. For a positive beta, a unit increase in the X variable increases, and for a negative beta, a unit increase in the X variable decreases the probability of acceptance.

Two methods for interpreting the hypothesized relationship between each dependent variable and the acceptance of amniocentesis have been noted. Formula (2)

uses the log odds of acceptance to rejection of amniocentesis as the dependent variable; formula (3) is based on the probability of acceptance of amniocentesis as the dependent variable. Yet because the interpretation of the betas based on formulas (2) and (3) is not intuitively obvious, another method for evaluating the significance of the regression coefficients should be considered. A third way to interpret the betas is in the form of the antilog of beta, or an odds ratio. This heuristic device is actually a ratio of a ratio. In logistic regression, beta is the estimated average change in the log odds of accepting amniocentesis per unit change in the independent (X) variable; taking the exponential (exp) of beta produces the odds ratio associating X with the dependent variable. To facilitate comprehension and to reduce the formula's complexity, explanations and illustrations will assume that the independent variable being investigated is dichotomous. In instances where X can be only 0 or 1, P_1 will signify the proportion of respondents who were coded as X=1 when Y=1; P_0 will represent the proportion of respondents coded as X=0 when Y=1. The odds ratio (also known as a "cross-products ratio") can then be calculated using the following equation:

$$\text{exp of beta} = [P_1(1-P_0)]/[P_0(1-P_1)] \qquad (4)$$

To illustrate with the current sample, the dichotomous variable measuring the presence or absence of insurance

coverage for amniocentesis will be employed for calculation of the odds ratio. Using SAS to perform a simple logistic regression analysis, insurance coverage has a beta of 1.3 in relation to the dependent variable. To convert this to an odds ratio, the total of 148 respondents who had insurance and accepted amniocentesis is divided by the total number of respondents who accepted amniocentesis; thus, P_1=148/199, or .74. Twenty-two respondents had no insurance but accepted amniocentesis; therefore, P_0=22/50, or .44. The odds ratio associating acceptance of amniocentesis and insurance coverage can then be derived by

exp of beta = [(.74)(.56)]/[(.44)(.26)] = 3.7

which is, in fact, the antilog of the beta coefficient (1.3) achieved in logistic regression. This can be interpreted as meaning that the odds in favor of accepting amniocentesis (the ratio of the probability of acceptance to the probability of rejection of amniocentesis) is 3.7 times greater for those who have insurance covering the procedure than for those who do not. To arrive at the original regression coefficient that expresses this odds ratio, taking the log of 3.7 produces a beta of 1.3. Thus, the exponential, or antilog, of beta can be interpreted as an odds ratio.

If there were no relationship between insurance coverage and acceptance of amniocentesis, the odds ratio

would equal 1.0 and the beta would be zero. Departures in either direction from 1.0 suggest association; the greater the departure, the stronger the relationship. If the beta is positive, the odds ratio will be greater than one; when the beta is negative, implying a negative relationship to the dependent variable, the odds ratio will be less than 1.0. To obtain a best estimate of the true odds ratio, a 95% confidence interval (CI) can be constructed around it using this formula:

$$95\%\ CI = \exp\ [\text{beta} \pm (1.96)(\text{standard error of beta})] \quad (5)$$

Continuing with the example of insurance coverage, a 95% confidence interval based on a standard error of beta of .33 can be computed. The lower limit is exp [1.3 -(1.96)(.33)] and the upper limit is exp [1.3 +(1.96)(.33)], yielding an interval between 1.9 and 7.0. This means that in 95% of all samples that could have been obtained from the reference population, the odds in favor of acceptance of amniocentesis would be 1.9 to 7.0 times greater for those who had insurance coverage than for those who did not have insurance covering the procedure.

The criteria used to assess the impact of several independent variables on the dependent variable in a multiple logistic regression are nearly identical to that explained for a simple regression model. The advantage of using more than one independent variable is that the impact

of each independent variable is adjusted for the effects of other X variables in the model. This suggests an additional method for assessing the relative strength of the variables in multiple logistic regression. The beta measures an increase in the log odds of acceptance of amniocentesis for each unit increase in a X variable. However, when comparing a continuous to a dichotomous independent variable, the relative impact of each is difficult to ascertain because the units of change for dichotomous and continuous variables are different. Therefore, a standardization of units of change becomes desirable. To achieve this one can standardize the coefficients (beta') using the following formula:

$$\text{beta}' = \text{beta (standard deviation of X)}, \qquad (6)$$

which allows for a measurement of change in the log of the odds in favor of acceptance of amniocentesis resulting from a change in one standard deviation of each X variable. Evaluating the various standardized betas, one can readily determine which independent variable(s) in a multiple logistic regression exert(s) the most influence on the outcome of the dependent variable (Schlesselman, 1982; Truett et al., 1967).

The manner in which the data were analyzed using logistic regression will be briefly explained. Distributions of the X variables in relation to the

dependent variable were inspected using contingency tables. Where there was a wide dispersion of answers causing more than one cell to have fewer than five observations, categories were collapsed (see Tables 3-5 for recoding). Each independent variable predicted to exert an influence on the dependent binary variable (acceptance or rejection of amniocentesis) was examined individually by a logistic procedure. Log odds ratios and confidence intervals were constructed for each significant variable ($p \leq .05$). Next, variables within each of the three subsets (social identity elements, reference group/significant others, and interpretation of meaning) were examined, using a full model to assess the impact of each variable while controlling for the effect of the other variables in the model. The statistical package used permits the "forcing" in of each variable, thus allowing one to evaluate the relative importance and significance of each variable in the subset analyses. After the first full subset model was run, the variable that showed the smallest relationship to the dependent variable was deleted and the regression was run again. This was repeated until only variables showing significant relationships to the dependent variable remained in the model.

A further consideration that guided the deletion of variables was a concern for multicollinearity. Pedhauzer

(1982) and others have discussed at length the problems that arise in interpretation of the betas when independent variables are highly intercorrelated. Multicollinearity can lead not only to serious distortion of the estimations of the betas but can also cause the reversal of their signs. Although there are no clear-cut remedies (Farrar and Glauber, 1967), a "solution" was adopted in this study. The full model of the hypothesized variables is always presented to demonstrate the impact of the variables while being controlled for by other stimulus variables. Subsequently, however, when variables were highly correlated ($r \geq .35$), the model would be run, alternately including each correlated variable to see whether it achieved significance when not adversely affected or underestimated due to multicollinearity. When a group of correlated variables appeared to represent a single underlying construct, an attempt was made to develop an index that would combine the variables into one unified measure. Cronbach's alpha was employed to assess the reliability of the index. When index constructs were not reliable, the variable that appeared to exert the most direct effect on the dependent variable was retained, and the highly correlated but less significant factors deleted.

To assess the goodness of fit of the final full models, standardized betas, odds ratios, the index c, R statistic

for each independent variable, and R^2 statistic for the model will be reported and used to determine the extent to which each hypothesis was supported. According to Hastings (1986), index c is equivalent to the area under a "receiver operating characteristic" (ROC) (Hanley and McNeil, 1982) and is proportional to the Wilcoxon-Mann-Whitney statistic (Leach, 1979) for determining whether predicted probabilities for the group of true positives differ from the predicted probabilities for the group of true negatives. In this study, the index c measures the probability of correctly identifying those who accept versus those who reject amniocentesis. The R statistic "measures the predictive ability of the model" (Hastings, 1986:271). Individual R statistics ("partial Rs") also provide a measure of the contribution of each variable, independent of the sample size. The R statistic is similar to the multiple correlation coefficient, after adjustment is made to penalize for the number of parameters estimated. R is derived from Akaike's information criterion and is identical to the likelihood ratio chi-square for a 2 x 2 contingency table (Atkinson, 1980). R takes on the value of 0 if the model offers a poor fit to the data and achieves a value of 1 if the model predicts perfectly. The R^2 statistic represents the proportion of log likelihood explained by the model.

To evaluate the final hypothesis, that social identity elements, reference groups/significant others, and interpretations of meaning will all affect the acceptance or rejection of amniocentesis, variables found to be significant in the initial subset runs were entered into the model and deleted one at a time until only significant independent variables remained.

Because the two questions measuring the influence of the respondents' doctors were asked of less than 60.0% of the sample, multiple regression runs on this subsample of respondents were examined in the same fashion as for the full sample. The models derived from these analyses will be compared and contrasted with those achieved in full-sample analyses.

Simple logistic regression

Within the social identity elements group, only two variables were significantly related to acceptance or rejection of amniocentesis (Table 6). To the extent that the four intervals in education (0-11, 12, 13-16, and 17 or more years of education) can be assumed to have an equivalent distance, an increase in education from one level to the next increased the prediction of the log odds of having amniocentesis by .4733. Converted to odds ratios, the odds in favor of accepting amniocentesis was 1.6 times greater among women who were high school graduates than for

Table 6. Simple logistic regression of social identity elements on acceptance or rejection of amniocentesis

Social identity elements	Beta	s.e.	X^2	R^a	Odds[b] Ratio	95% Confidence Interval
Intercept	.6195	.3158	3.85			
Education	.4733	.1817	6.78**	.138	1.61	(1.12, 2.29)
Intercept	.9359	.3392	7.61			
Spouse's education	.2680	.1806	2.20	.029		
Intercept	1.1144	.2515	19.64			
Ever divorced	.4236	.3242	1.71	.000		
Intercept	1.0199	.2496	16.69			
Number of children	.2727	.1554	3.08	.066		
Intercept	.5996	.2352	6.50			
Insurance covering amniocentesis	1.3065	.3279	15.87***	.236	3.69	(1.94, 7.02)

[a]The R statistic is similar to a multiple correlation coefficient, after corrections are made to penalize for numbers of parameters estimated, measurring the predictive ability of the model; when squared, it is similar to R^2 and can be intepreted as estimating the proportion of log likelihood explained by the model (Atkinson, 1980; Hastings, 1986).

[b]Odds ratios are calculated and 95% confidence intervals are constructed only for variables that are significant.

**Significant at .01 level.

***Significant at .001 level.

women with less than high school education; the odds in favor of accepting the procedure was 1.6 times greater for those with at least some college than for those who are high school graduates; and the odds in favor of accepting amniocentesis was 1.6 times greater for those with graduate level education than for those with at least some college. Moreover, the odds in favor of accepting amniocentesis was 3.7 times greater for those who had insurance for the procedure than for those without it.

Among the seven variables measuring significant other and reference group support or influence, four showed a significant relationship to the dependent variable (Table 7). The odds in favor of acceptance was nearly 16 times greater for women who reported that their husbands thought they should have the procedure than for those whose husbands reportedly left the decision about amniocentesis up to them. Those whose friends and neighbors gave them support for their decisions were significantly more likely to undergo amniocentesis than were those who had less support or no support, as were respondents whose doctors gave them support for their decisions. The odds in favor of acceptance was 5.7 times greater among women who said their doctors thought they should have amniocentesis than for those whose doctors left the decision up to them.

Every one of the seven variables measuring respondents'

Table 7. Simple logistic regression of significant other and reference group variables on acceptance or rejection of amniocentesis

Reference group or significant others support	Beta	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-2.1003	.4590	20.94			
Husband[a] thinks woman should have amniocentesis	2.7706	.3492	62.95***	.501	15.97	(8.05, 31.66)
Intercept	.7713	.3920	3.87			
Support from husband[a] for woman's decision	.3978	.2363	2.83	.058		
Intercept	1.1438	.2331	24.07			
Support from parents for woman's decision	.1829	.1282	2.04	.012		

[a]Or child's father.
***Significant at .001 level.

Table 7. (continued)

Reference group or significant others support	Beta	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	.9327	.2146	18.89			
Support from friends for woman's decision	.3772	.1399	7.27**	.145	1.46	(1.11, 1.92)
Intercept	-1.1822	.5132	5.31			
Doctor thinks woman should have amniocentesis	1.7464	.3710	22.16***	.345	5.73	(2.77, 11.86)
Intercept	-.1904	.3403	.31			
Support from doctor for woman's decision	1.4189	.2863	24.56***	.389	4.13	(2.36, 7.24)
Intercept	1.1330	.2162	27.45			
Religious strength	.1718	.1107	2.41	.040		

**Significant at .01 level.

interpretation of risks and norms or attitudes about abortion was significantly related to the probability of having amniocentesis (Table 8). Using one of the variables for illustrative purposes, with each higher level of increased chance of complications associated with amniocentesis a woman was willing to accept, there was an increase of 1.63 in the log odds of having the procedure. Translating this into odds ratios, the odds in favor of accepting amniocentesis was 5.1 times greater for a woman willing to accept a 20.0% or greater chance of test complications than for one willing to accept a 5.0% chance of test complications.

Multiple logistic regression: full sample

Thirteen of the proposed nineteen variables showed a significant bivariate relationship to the dependent variable. Two of these, however, were measures investigating the influence of and support from the women's physicians. Because these questions were asked of only 60.0% of the sample, multiple logistic regression analysis of this subsample of 148 women will be undertaken in the following section.

To test hypothesis one, that women and their spouses who have higher education, have not been previously divorced, who have fewer children, and have insurance covering the procedure would be more likely to accept amniocentesis, a

Table 8. Simple logistic regression of interpretation of meaning variables on acceptance or rejection of amniocentesis

Interpretation of meaning	Beta	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-.0374	.3884	.63			
Perceived accuracy of amniocentesis	1.1096	.2423	20.96***	.278	3.03	(1.88, 4.88)
Intercept	.9705	.2067	22.04			
Perceived odds of having fetus with Down syndrome	.5797	.2097	7.64**	.151	1.79	(1.18, 2.69)
Intercept	.0810	.4016	.04			
Perceived risk of complications with amnioniocentesis	.6855	.1975	12.05***	.205	1.98	(1.35, 2.92)

**Significant at .01 level.
***Significant at .001 level.

Table 8. (continued)

Interpretation of meaning	Beta	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-1.5294	.4089	13.99			
Chances of test complication woman is willing to accept	1.6320	.2322	49.40***	.437	5.11	(3.24, 8.06)
Intercept	.0409	.2871	.02			
Agree that life should be preserved at all times	.6139	.1222	25.23***	.305	1.85	(1.45, 2.35)
Intercept	-.8995	.3875	5.39			
Approval of abortion to avoid birth defects	.8693	.1439	36.49***	.372	2.39	(1.80, 3.16)
Intercept	.1969	.2824	.49			
Strength to which feelings about abortion are based on religious teachings	.6365	.1399	20.70***	.274	1.89	(1.44, 2.49)

multiple logistic regression analysis was performed. In the initial run, only insurance coverage showed a significant relationship to the probability of accepting amniocentesis (Table 9). The variable with the smallest chi-square (divorce) was eliminated and the model was run again. This was repeated until two variables, education and insurance covering amniocentesis, remained (Table 10). Because education was significantly correlated with spouse education ($r=.57$, $p=.001$), education appeared not to be significant in the initial full-model run. However, once spouse education was deleted, education proved to be significantly related to the probability of accepting amniocentesis, after controlling for the effect of insurance coverage. Thus, for example, the odds in favor of acceptance was 1.5 times greater for a woman with high school education than for a woman with 11 or fewer years of schooling, after controlling for the effect of having insurance. And the odds in favor of acceptance was 3.4 times greater for a respondent with insurance covering the procedure than for a respondent without such insurance coverage, after controlling for the effect of education. When the standardized betas were compared, insurance was nearly twice as important as is education. Using the multiplicative effect of odds ratios (Schlesselman, 1982), the impact of having both insurance coverage and higher education can be estimated. Thus, the

Table 9. Multiple logistic regression of social identity elements on acceptance or rejection of amniocentesis (N=247)

Social identity elements	Beta	Beta'[a]	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-.1517		.4596	0.11			
Education	.3087	.2824	.2271	1.85	.000		
Spouse's education	-.0539	-.0479	.2278	0.06	.000		
Ever divorced	.3440	.1633	.3508	0.96	.000		
Number of children	.1234	.1288	.1648	0.56	.000		
Insurance covering amniocentesis	1.2700	.5935	.3424	13.76**	.219	3.56	(1.82, 6.97)
index c[b] .688							
R^2 for model 4.8%							

[a]Standardardized beta.
[b]The index c is proportional to the Wilcoxon-Mann-Whitney statistic for testing whether predicted probabilities for the group of true positives are different from predicted probabilities for the group of true negatives (Leach, 1979; Hastings, 1986).
**Significant at .01 level.

Table 10. Multiple logistic regression of social identity elements on acceptance or rejection of amniocentesis, reduced model (N=249)

Social identity elements	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	.0519		.3523	0.02			
Education	.3739	.3436	.1836	4.15*	.093	1.45	(1.01, 2.08)
Insurance covering amniocentesis	1.2106	.5646	.3337	13.16**	.211	3.36	(1.74, 6.45)
index c .689							
R^2 for model 6.6%							

*Significant at .05 level.
**Significant at .01 level.

odds in favor of acceptance was 4.9 times greater (1.45 times 3.36) among respondents who were high school graduates and who had insurance coverage for amniocentesis than among those with less than high school and who didn't have insurance coverage for the test; likewise, the odds in favor of acceptance was 4.9 times greater for those with at least some college and insurance covering amniocentesis than for high school graduates without such insurance; and the odds in favor of acceptance was 4.9 times greater for those with graduate-level education and insurance covering amniocentesis than for those with at least some college and no insurance coverage for amniocentesis.

Although both insurance and education were significantly related to the acceptance or rejection of the procedure, the model itself shows a poor fit. The more important variable, insurance coverage, predicts just 4.5% of the probability of acceptance of amniocentesis and the model itself contributes only 6.6% to the proportion of log likelihood explained. The probability of correctly differentiating between acceptors and rejectors is a modest 0.69.

In the full model examining the influence of and support from reference groups and significant others, upon which hypothesis two was based, only one of five variables was statistically significant (Table 11). The odds in favor

Table 11. Multiple logistic regression of significant other and reference group variables on acceptance or rejection of amniocentesis, full model (N=243)

Interaction with/support from significant others reference groups	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-3.3656		.8229	16.73			
Husband thinks should have amniocentesis	2.8105	2.0065	.3752	56.10***	.476	16.62	(7.97, 34.67)
Husband's support for decision	.2233	.1408	.3525	0.40	.000		
Parents' support for decision	.1772	.2228	.2180	0.66	.000		
Friends' support for decision	.1535	.1857	.2308	0.44	.000		
Religious strength	.3136	.4903	.1756	3.19	.071		
index c	.931						
R^2 for model	48.0%						

***Significant at .001 level.

of acceptance among respondents who reported that their husbands thought they should have amniocentesis was 16.6 times greater than for those whose husbands reportedly left the decision up to them. After eliminating the other four variables sequentially, this variable assessing the wife's report of her husband's influence was still the only significant predictor variable, and the odds ratio remained largely unchanged (Table 12). Although support from friends was significant in the bivariate analysis, it was no longer significant here when controlled for by the variable measuring the respondent's view of her husband's opinion about accepting or rejecting the test. An attempt was made to construct an index of the three emotional support measures inasmuch as support from parents and support from friends and neighbors were highly correlated ($r=.45$, $p=.001$). However, Cronbach's alpha was only .45, suggesting an insufficient internal consistency of these items.

For the model as a whole, the index c is quite high, indicating that the area under the receiver operating characteristic (ROC) was able to clearly discriminate between those who would accept or reject amniocentesis given the influence of what the respondent said her husband thought. Although it contains only one variable, its predictive ability appeared to be good, explaining 49.4% of the log likelihood of accepting amniocentesis.

Table 12. Multiple logistic regression of significant other and reference group variables on acceptance or rejection of amniocentesis, final model (N=246)

Interaction with/support from significant others reference groups	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-2.1003		.4590	20.94			
Husband thinks should have amniocentesis	2.7706	1.988	.3492	62.95***	.501	15.97	(8.05, 31.66)
index c	.902						
R^2 for model	49.4%						

***Significant at .001 level.

Although each of the seven variables within the interpretation of meaning group used to test hypothesis three was significantly related to the dependent variable in bivariate analysis, only three proved to be statistically significant in the full model. The four measures that examined the women's perceptions of risks and odds relating to amniocentesis, their estimation of the chances of complications from the test they would be willing to accept, and their perceived susceptibility to having a Down syndrome child were somewhat intercorrelated (a high of r=.17, p=.001), but insufficiently so to create a reliable index of risk perceptions (Cronbach's alpha=.36).

The three questions relating to norms and attitudes about abortion or the sanctity of life were much more highly intercorrelated (.51, .56, and .61, p=.001). Using Cronbach's method of assessing the reliability of an index composed of these three measures, an alpha of .79 was achieved. Therefore, values from the items were summed and, to create an average response across items, were divided by three. This measure then was re-entered into the model with the four odds/risks variables (Table 13). The index of norms about abortion, the women's willingness to accept higher chances of complications, and their perception of the test's ability to accurately identify a fetus with Down syndrome all proved to be significantly related to

Table 13. Multiple logistic regression of interpretation of meaning variables on acceptance or rejection of amniocentesis, full model (N=237)

Interpretation of meaning	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-4.5927		.9754	22.17			
Perceived accuracy of amniocentesis	.8046	.4828	.3491	5.31*	.119	2.24	(1.12, 4.43)
Perceived odds of having fetus with Down syndrome	.3345	.3094	.2928	1.31	.000		
Perceived risk of complications with amnioniocentesis	.4637	.3741	.2796	2.75	.057		
Chances of test complication woman is willing to accept	1.2515	1.4949	.2597	23.22***	.302	3.50	(2.10, 5.82)
Index of norms and attitudes about abortion	.6081	.6160	.2333	6.80**	.143	1.84	(1.16, 2.90)
index c	.898						
R^2 for model	39.2%						

*Significant at .05 level.
**Significant at .01 level.
***Significant at .001 level.

acceptance of the procedure.

These three variables remained significant during the sequential deletion of nonsignificant variables (Table 14). After controlling for the effect of the other two variables, a woman's willingness to accept chances of complications with amniocentesis was by far the most important factor as indicated by the standardized betas, while her estimation of the test's accuracy was least important, although still significant. For each level of increased chance of test complications a woman was willing to accept, the odds in favor of acceptance was increased by 4.1. To illustrate the multiplicative effect of these three variables, the odds in favor of acceptance was 17.6 times greater for a respondent who perceived the test to have a very high chance of detecting a fetus with Down syndrome, who was willing to accept a 20.0% or greater chance of complications with amniocentesis, and who held very strong proabortion norms or attitudes than for a respondent who perceived the test's accuracy to be moderately high, who would accept a 5.0% chance of test complications, and who held strong proabortion norms or attitudes. The final model as a whole suggested a reasonably good fit to the data, with an index c of 0.89 and an R^2 of 40.1%.

In the final analysis, assessing whether the fourth hypothesis could be supported, only two variables were

Table 14. Multiple logistic regression of interpretation of meaning variables on acceptance or rejection of amniocentesis, final model (N=241)

Interpretation of meaning	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-3.7966		.7798	23.71			
Perceived accuracy of amniocentesis	.8455	.5149	.3314	6.51*	.136	2.33	(1.22, 4.46)
Chances of test complication woman will accept	1.4219	1.7024	.2499	32.38***	.353	4.14	(2.54, 6.76)
Index of attitudes about abortion	.5989	.6050	.2225	7.24**	.147	1.82	(1.18, 2.82)

index c .890

R^2 for model 40.1%

*Significant at .05 level.
**Significant at .01 level.
***Significant at .001 level.

significant in the full model run (Table 15). Judging from an index c of 0.97 and an R^2 of 62.9%, the model appeared to provide a good fit of the data, and to have theoretical and substantive merit. However, in keeping with the attempt to discern the most parsimonious model, nonsignificant variables were sequentially deleted. In the final model, two variables remained significant (Table 16). After controlling for the influence of women's willingness to accept higher chances of complications with amniocentesis, the odds of acceptance was 14.6 times greater among those who stated that their husbands thought they should have the procedure than among the women whose husbands reportedly left the decision about amniocentesis up to them. Moreover, after controlling for women's reports of their husbands' opinions about accepting amniocentesis, the odds in favor of acceptance was 4.2 times greater for those willing to accept progressively higher chances of complications with amniocentesis. The model's goodness of fit was only slightly reduced with the elimination of the four other variables, showing an index c of 0.96 and an R^2 of 61.9%. This would suggest a good fit to the data, since more than half of the log likelihood of accepting amniocentesis was explained. A diagram representing this parsimonious and, apparently, quite statistically significant model is presented in Figure 4. However, while parsimonious, the

Table 15. Multiple logistic regression of significant variables from social identity, reference group/significant other, and interpretation of meaning variables on acceptance or rejection of amniocentesis, full model (N=238)

Self, significant other, and interpretation of meaning variables	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-6.1197	1.0307	2232	5.03			
Education	- .0116	-.0107	.3644	.00	.000		
Insurance covering amniocentesis	.1419	.0665	.6774	.04	.000		
Husband thinks should have amniocentesis	2.6383	1.9136	.4543	33.73***	.366	13.99	(5.74, 34.08)
Perceived accuracy of amniocentesis	.3801	.2321	.4528	.70	.000		
Chances of test complication woman will accept	1.3205	1.5684	.3538	13.93***	.225	3.75	(1.87, 7.49)
Index of norms and attitudes about abortion	.5120	.5123	.3221	2.53	.047		
index c	.966						
R^2 for model	62.9%						

***Significant at .001 level.

Table 16. Multiple logistic regression of significant variables from social identity, reference group/significant other, and interpretation of meaning variables on acceptance or rejection of amniocentesis, final model (N=243)

Self, significant other, and interpretation of meaning variables	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-4.6660		.8814	28.02			
Husband thinks should have amniocentesis	2.6817	1.9322	.4120	42.37***	.409	14.61	(6.52, 32.76)
Chances of test complication woman will accept	1.4245	1.6898	.3128	20.74***	.279	4.16	(2.25, 7.67)
index c	.955						
R^2 for model	61.9%						

***Significant at .001 level.

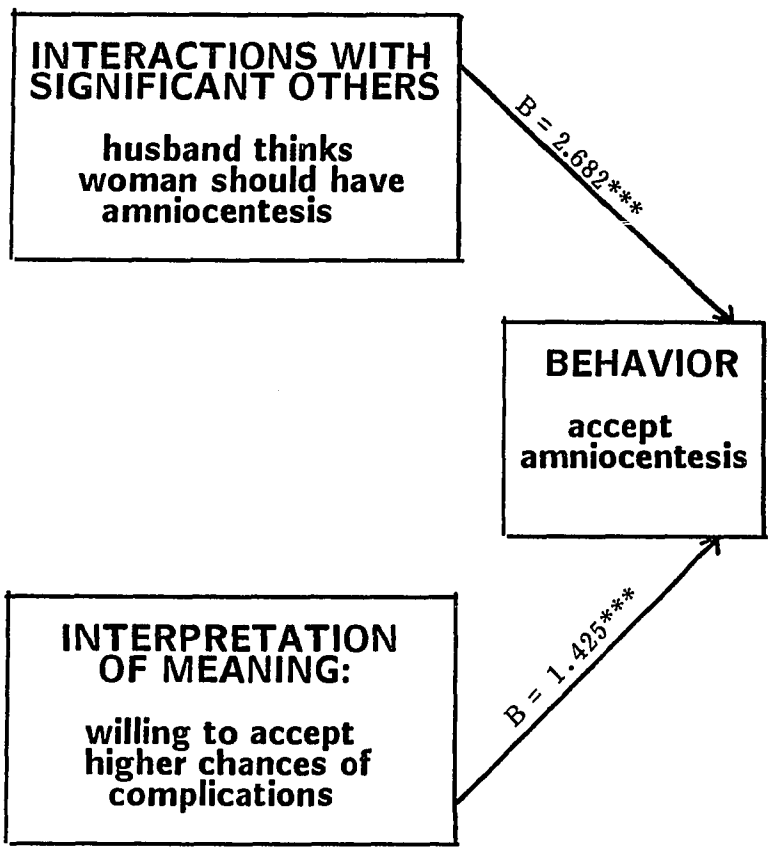

Figure 4. Diagram of direct relationships of independent variables to the acceptance of amniocentesis, full sample

reduced model lacks a substantive, theoretical appeal. Therefore, an attempt was made to discern why the four factors previously found to be significant were eliminated from the final reduced model.

Figure 5 summarizes the results. Only variables found to be significant in subset analyses were included. Causal ordering was assumed; hence, social identity elements were placed as exogenous variables, attitudes/norms and perceptions were intermediate factors, and variables found to be directly significant were presented as endogenous predictors of acceptance of amniocentesis. Because of the assumed causal order, no attempt has been made to present a full path diagram. Instead, Figure 5 should be considered a heuristic device that demonstrates both statistically significant and theoretically relevant factors that influence the acceptance or rejection of amniocentesis.

Using simple logistic regression, education was found to be significantly related to both insurance coverage (beta=.370, p=.05) and to the respondents' report of whether husbands thought they should accept amniocentesis (beta=.357, p=.05). Insurance coverage, too, was significantly related to the variable measuring the husband's perceived influence (beta=1.309, p=.001), indicating that social identity elements may exert an indirect effect on acceptance of amniocentesis.

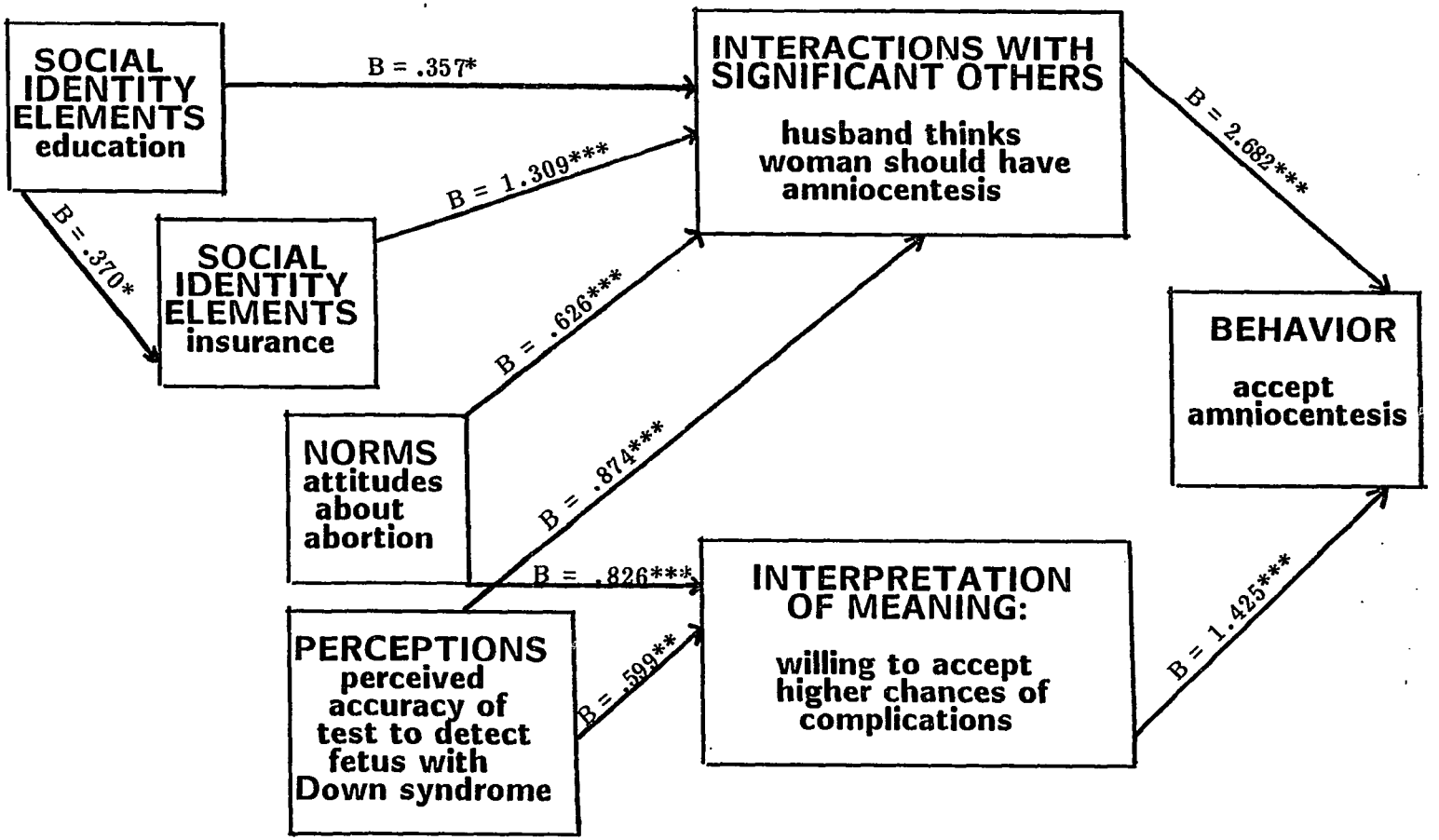

Figure 5. Heuristic diagram of direct and indirect relationships of independent variables to the acceptance of amniocentesis, full sample

Two interpretation of meaning variables also appeared to exert significant indirect influence on women's decisions regarding amniocentesis. A woman's perception of the test's accuracy was significantly related to the variable measuring the woman's report of her husband's opinion (beta=.874, p=.001) and to the chances of complications from amniocentesis a woman was willing to accept (beta=.599, p=.001). The index of women's norms or attitudes about abortion was likewise related to these two variables (beta=.626, p=.001 and beta=.826, p=.001, respectively). This heuristic model, then, demonstrates both the direct and indirect effects of social identity elements, reference groups or significant others, and interpretations of meaning on the acceptance of amniocentesis.

Multiple logistic regression: subsample

The 148 women who had been asked both questions about their doctors' opinion regarding their seeking amniocentesis and their doctors' support for their decisions were selected out of the full sample and multiple logistic regression procedures were performed on this subsample. In examining the first subset of variables, social identity elements, only insurance coverage appeared to have a significant relationship with acceptance or rejection of amniocentesis (Table 17). As was true with the larger sample, because of problems of multicollinearity of women's education with

Table 17. Multiple logistic regression of subsample social identity elements on acceptance or rejection of amniocentesis (N=146)

Social identity elements	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	.4243		.6193	0.47			
Education	-.1121	-.1006	.2977	0.14	.000		
Spouse's education	.1719	.1593	.2811	0.37	.000		
Ever divorced	-.0015	.0007	.4556	0.00	.000		
Number of children	.0504	.0534	.2067	0.06	.000		
Insurance covering amniocentesis	1.1978	.5318	.4433	7.30**	.191	3.31	(1.39, 7.90)
index c .679							
R^2 for model 0.0%							

**Significant at .01 level.

spouses' education (r=.58, p=.001), the betas of these two variables were somewhat distorted. Even after interchangeably entering the two variables into the model, insurance coverage alone was selected as significant. This suggested that the subsample had somewhat different characteristics than the full sample. However, investigation of the range and categories of the education variable and a t-test of means (t=1.1, NS) for the full sample and subsample showed no statistically significant differences. Thus, the lack of significance of education may be a reflection of the smaller sample size alone. Even in the full model, education was only significant at the .05 level, whereas most of the other significant variables had much higher p-values, suggesting that education, when controlled for by other factors in the model, exerted a fairly modest influence on decision outcome.

Within the subsample, then, the odds in favor of accepting amniocentesis was 3.3 times greater for women with insurance coverage for amniocentesis than for women without this kind of insurance (Table 18). As with the full sample, however, this single social identity element provided a poor fit to the data, explaining only 3.6% of the proportion of log likelihood; the index c showed that the model's ability to differentiate between acceptors and rejectors was only marginal (0.63).

Table 18. Multiple logistic regression of subsample social identity elements on acceptance or rejection of amniocentesis, reduced model (N=146)

Social identity elements	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	.5798		.3338	3.02			
Insurance covering amniocentesis	1.1802	.5217	.4298	7.54**	.193	3.26	(1.40, 7.56)
index c .627							
R^2 for model 3.6%							

**Significant at .01 level.

Within the full subsample model examining the influence of significant others and reference groups, three variables achieved statistical significance (Table 19). However, as nonsignificant variables were deleted sequentially, the variable measuring respondents' religious strength no longer remained significant. This model was particularly affected by problems of multicollinearity, where the two variables assessing the influence of the women's doctors were moderately correlated (r=.47, p=.001), the variable measuring the husband's reported opinion about whether the woman should accept amniocentesis was correlated with the woman's report of what her doctor thought (r=.39, p=.001), husband's support was correlated with doctor's support (r=.31, p=.001), friends' support (r.=17, p=.04), and parents' support (r=.27, p=.01), and parents' support and friends' support, as with the full sample, were correlated (r=.44, p=.001). When Cronbach's alpha was used to assess the reliability of an underlying construct measuring support, an alpha of .58 was achieved, which is fairly substantial, but not sufficient to form an index tapping the underlying construct of emotional support for the woman's decision. Further, when viewing the items from a theoretical standpoint, a woman's perception of support from her husband or her doctor each has substantively different meanings; neither do these types of support seem

Table 19. Multiple logistic regression of significant other and reference subsample variables on acceptance or rejection of amniocentesis, full model (N=143)

Interaction with/support from significant others reference groups	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-3.3078		1.1234	8.67			
Husband thinks should have amniocentesis	3.9873	1.8476	.8386	22.61***	.386	53.91	(10.42, 278.93)
Doctor thinks should have amniocentesis	.7370	.4436	.5396	1.87	.000		
Husband's support for decision	.1020	.0676	.4619	0.05	.000		
Doctor's support for decision	2.3343	1.1609	.7765	9.04**	.225	10.32	(2.25, 47.29)
Parents' support for decision	.0641	.0808	.2767	0.05	.000		
Friends' support for decision	.0310	.0373	.3096	0.01	.000		
Religious strength	.4571	.7694	.2261	4.09*	.123	1.58	(1.01, 2.46)
index c .951							
R^2 for model 44.5%							

*Significant at .05 level.
**Significant at .01 level.
***Significant at .001 level.

conceptually similar to support from parents or friends. Each group or significant other would very probably provide a different type of support, each of which would hold different interpretations of meaning for the respondent. Therefore, although it could be argued that these different types and perceptions of support nevertheless generated a global sense of well-being for the individual, it was decided that each item would be entered alternately, thereby avoiding problems of multicollinearity while maintaining more conceptual clarity. As a result, two measures remained in the model (Table 20). While controlling for the effect of the doctor's support for her decision, the odds in favor of acceptance was 51.5 times greater for a woman who said her husband felt she should have the procedure than for a respondent whose husband left the decision up to her. Further, when controlling for the effect of what the husband thought, the odds in favor of acceptance was nearly 12 times greater for women whose doctors gave them strong emotional support for their decision about amniocentesis than for the women who received less strong or no support from their doctors for their decision regarding the test.

Within the subsample exploration of the interpretation of meaning variables, Cronbach's alpha of the three abortion attitude items suggested a strong underlying construct (alpha=.75), so, as with the full sample, the index of norms

Table 20. Multiple logistic regression of significant other and reference subsample variables on acceptance or rejection of amniocentesis, final model (N=146)

Interaction with/support from significant others reference groups	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-1.3370		.4589	8.49			
Husband thinks should have amniocentesis	3.9416	1.8373	.7221	29.80***	.437	51.50	(12.51, 212.07)
Doctor's support for decision	2.4736	1.2336	.6613	13.99***	.287	11.87	(3.66, 43.37)
index c .929							
R^2 for model 47.5%							

***Significant at .001 level.

and attitudes about abortions was entered into the model along with the four risk items (which did not achieve a substantial Cronbach's alpha). Only the woman's self-assessed willingness to accept chances of complications with amniocentesis achieved statistical significance in the full model (Table 21), again because of problems with multicollinearity of the abortion index with some of the risk items. However, as variables were alternately entered and deleted, the final model consisted of two variables that were significantly related to accepting amniocentesis (Table 22). After controlling for the norms and attitudes abortion index, the odds in favor of acceptance was 5.7 times greater for a woman willing to accept a 20.0% or higher chance of complications associated with amniocentesis than for a woman who would accept a 5.0% chance of test complications. The odds ratio of the abortion norms and attitudes index, after controlling for the women's risk-accepting assessments, was relatively small (1.8). Examination of the standardized betas showed that the item measuring a woman's willingness to accept chances of complications from amniocentesis was nearly four times more important than the norms and attitudes abortion index in predicting the log odds of a respondent's acceptance of amniocentesis. The fit of the model is quite good, showing an R^2 of 40.3%, and an index c of 0.90.

Table 21. Multiple logistic regression of subsample interpretation of meaning variables on acceptance or rejection of amniocentesis, full model (N=146)

Interpretation of meaning	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-4.5614		1.3947	10.70			
Perceived accuracy of amniocentesis	.2944	.1536	.5371	0.30	.000		
Perceived odds of having fetus with Down syndrome	.0905	.0816	.3778	0.06	.000		
Perceived risk of complications with amnioniocentesis	.6544	.5339	.3826	2.93	.079		
Chances of test complication woman is willing to accept	1.5978	1.8609	.3795	17.72***	.326	4.94	(2.35, 10.40)
Index of norms and attitudes about abortion	.5661	.5619	.3086	3.37	.096		
index c	.898						
R^2 for model	38.7%						

***Significant at .001 level.

Table 22. Multiple logistic regression of subsample interpretation of meaning variables on acceptance or rejection of amniocentesis, final model (N=146)

Interpretation of meaning	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-2.9206		.8276	12.45			
Chances of test complication woman will accept	1.7348	2.0205	.3567	23.65***	.382	5.67	(2.82, 11.40)
Index of norms and attitudes about abortion	.5940	.5895	.2944	4.07*	.118	1.81	(1.02, 3.23)
index c	.895						
R^2 for model	40.3%						

*Significant at .05 level.
***Significant at .001 level.

The final full subsample model (in which significant variables from the social identity elements, significant other, and interpretation of meaning subset analyses were entered) demonstrated a better fit to the data than any model previously examined either in the full sample or the subsample analyses (Table 23). Here, 66.9% of the log likelihood was explained, and the model showed a good ability to differentiate between acceptors and rejectors of amniocentesis (index c = 0.98).

In keeping with an attempt to find the most parsimonious model, nonsignificant variables were sequentially eliminated, leaving a model in which three variables achieved statistical significance (Table 24). Examining the standardized betas, it appeared that while controlling for the effect of other variables in the model, both the woman's perceptions of her husband's opinion and her willingness to accept chances of test complications were the most important measures in predicting the acceptance or rejection of amniocentesis, demonstrating nearly twice the influence of the doctor's support for the woman's decision. This reduced model achieved the highest predictive ability of all models examined, explaining 68.9% of the log likelihood of acceptance of amniocentesis. Figure 6 presents a diagram of the relationships of variable in the final reduced model.

Table 23. Multiple logistic regression of significant variables from social identity, reference group/significant other, and interpretation of meaning variables subsample, on acceptance or rejection of amniocentesis, full model (N=144)

Self, significant other, and interpretation of meaning variables	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-8.1801		2.2787	12.89			
Insurance covering amniocentesis	.4049	.1806	.9034	.20	.000		
Husband thinks should have amniocentesis	2.9593	2.1239	.7141	17.17***	.324	19.28	(4.76, 78.17)
Doctor's support for decision	2.3956	1.1945	.9963	5.78*	.162	10.97	(1.56, 77.35)
Chances of test complication woman will accept	1.7768	2.0407	.7288	5.94*	.165	5.91	(1.42, 24.66)
Index of norms and attitudes about abortion	.5658	.5498	.5227	1.17	.000		
index c	.977						
R^2 for model	66.9%						

*Significant at .05 level.
***Significant at .001 level.

Table 24. Multiple logistic regression of significant variables from social identity, reference group/significant other, and interpretation of meaning variables subsample, on acceptance or rejection of amniocentesis, final model (N=146)

Self, significant other, and interpretation of meaning variables	Beta	Beta'	s.e.	X^2	R	Odds Ratio	95% Confidence Interval
Intercept	-7.1734		1.9156	14.02			
Husband thinks should have amniocentesis	3.0925	2.2102	.7049	19.25***	.344	22.03	(5.53, 87.72)
Doctor's support for decision	2.2474	1.1208	.9439	5.67*	.159	9.46	(1.49, 60.19)
Chances of test complication woman will accept	2.0645	2.3550	.7271	8.06**	.204	7.88	(1.90, 32.77)
index c	.973						
R^2 for model	68.9%						

*Significant at .05 level.
**Significant at .01 level.
***Significant at .001 level.

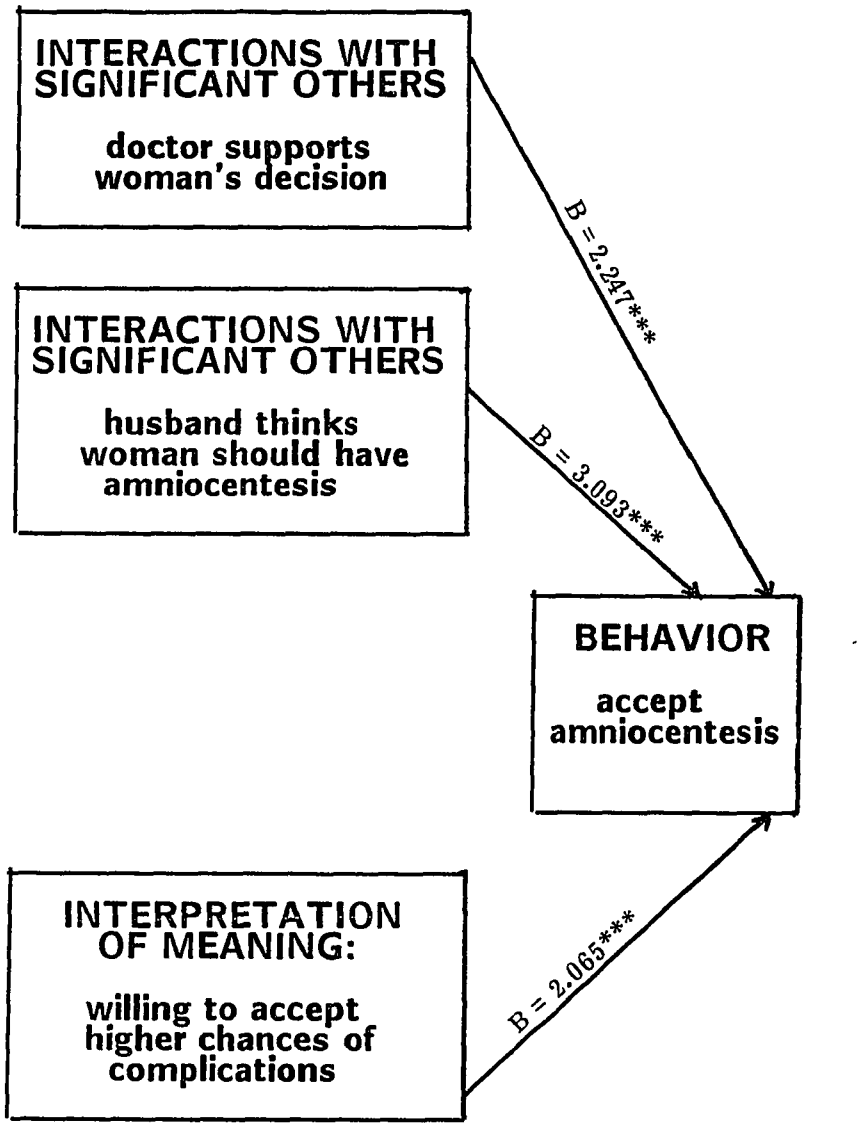

Figure 6. Diagram of direct relationships of independent variables to the acceptance of amniocentesis, subsample

Although the final model achieved considerable statistical significance, as with the full sample, this parsimonious and highly explanatory model does not fully capture the factors that influence decision outcome for women at genetic risk. Figure 7 represents a heuristic tool to better conceptualize the processes these women went through to achieve their decisions regarding amniocentesis. Having insurance coverage significantly influenced the woman's perception of both her husband's opinion and the doctor's support (beta=1.519, p=.001, beta=.937, p=.05, respectively). Attitudes about abortion significantly affected the woman's perception of her husband's opinion (beta=.558, p=.001) as well as the woman's willingness to accept chances of complications to undergo amniocentesis (beta=.854, p=.001).

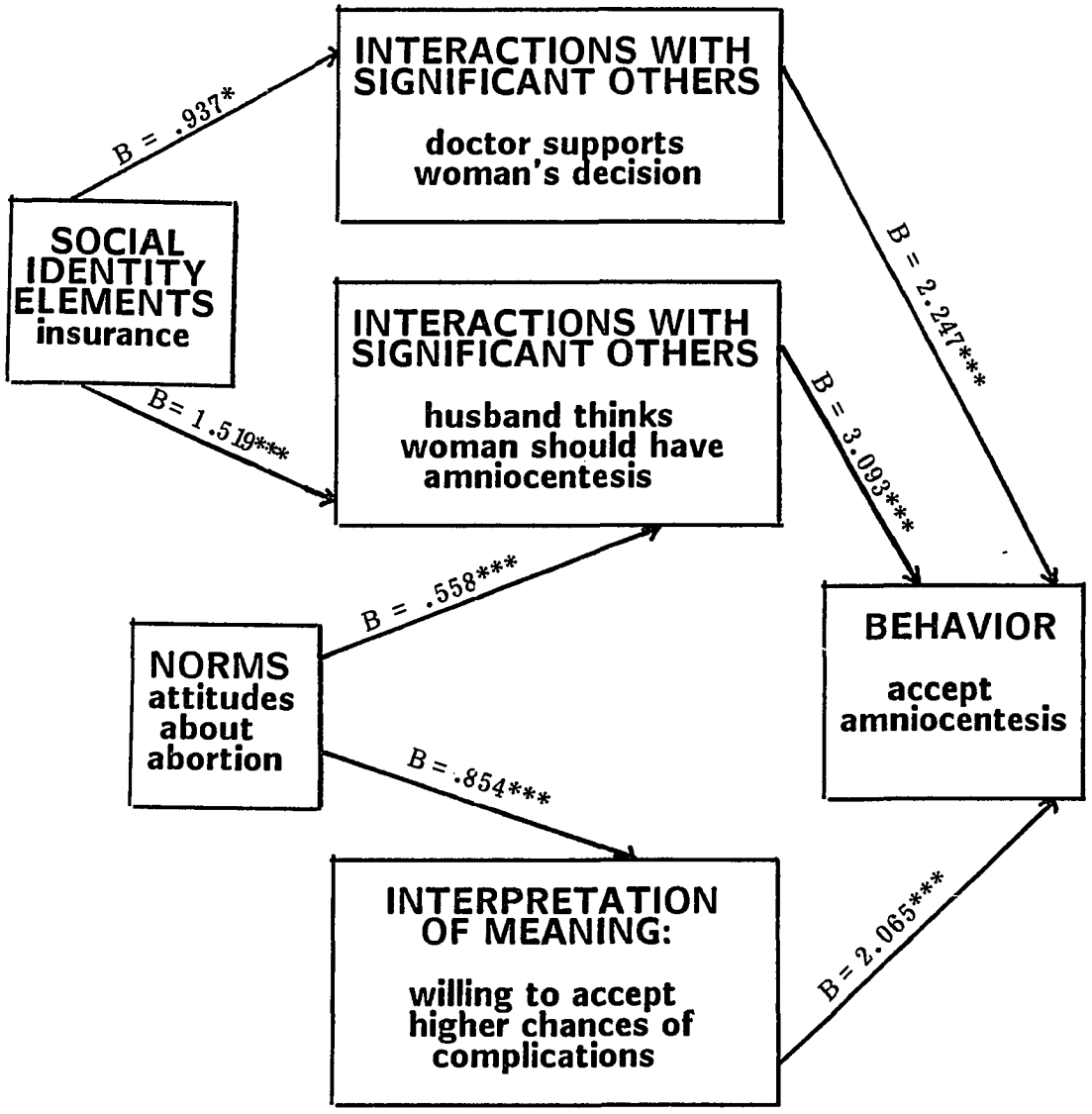

Figure 7. Heuristic diagram of direct and indirect relationships of independent variables to the acceptance of amniocentesis, subsample

CHAPTER V: DISCUSSION

Summary of Findings

Examination of the data using logistic regression showed that none of the four hypotheses were supported unqualifiedly. Within each of the subset analyses, a majority of the hypothesized variables were eliminated. However, significant relationships were found within each of the social identity, significant other/reference group, and interpretation of meaning variables. In the final models, significant others (husbands and/or doctors) and interpretations of meaning (women's willingness to accept chances of complications from amniocentesis) exerted strong direct influence on the women's acceptance of amniocentesis. Social identity factors, perceptions, and norms or attitudes also affected the women's decisions, albeit indirectly. Thus, although the detailed hypotheses achieved only marginal support, the underlying conceptual hypotheses were confirmed, and the models derived from these theoretical predictions offered a good fit to the data.

Discussion of Findings

When controlled for by other significant variables, none of the measures of social identity achieved direct statistical significance in relation to acceptance of amniocentesis in the final models. The lack of direct influence by eduction is most surprising, as this measure has been a consistent significant predictor in previous research. In the current study, the overall high educational status of both groups (accepters, mean of 14.5 years, rejectors, 13.4 years) may be a factor. It also could be that this study captures the gradual change in consumer behavior in medical settings. Education measures in earlier studies seemed to indicate the presence of a socioeconomic gradient, which reduced access to treatment among lower status groups. More recent health-related research has demonstrated that lower education and/or income no longer present the barriers they once did to medical usage (Robert Wood Johnson Foundation, 1983). Now, as women have to contend with fewer structural constraints and, perhaps, are more aware of their genetic risks and these services, definitions of the situation, norms, and the perceived influence of significant others, particularly one's spouse and physician, then may take precedence over measures of educational attainment as determinants of acceptance or rejection of amniocentesis. Thus, for both

acceptors and rejectors, education may affect their perceptions and construction of reality, but does not directly influence their decisions to accept or reject amniocentesis. In future research among fairly highly educated respondents, education level should be treated not so much as a sociostructural deterrent but as a mechanism that affects cognitive processing and reference group interactions and interpretations.

Although the trend was in the hypothesized direction, spouses' education exerted no influence either in bivariate or multivariate logistic analyses. This measure had been significant in studies examining women's correct assessment and retention of genetic risks, probabilities, and diagnoses (Emery et al., 1979). Inasmuch as "correct" information appears to exert minimal influence on actual outcome (Antley, 1976) and as this study did not deal with objective risk factors, this variable probably should not have been included in the model. At most, given its strong correlation with wives' education (r=.58), this measure may simply reflect a basic social reality: people tend to maintain relationships with others of similar socioeconomic status (Byrne, 1971; Nahemow and Lawton, 1975). At the same time, although no measure was available to assess this, higher education among women may be linked to their increased assertiveness both in their personal relationships

and in health-care settings. Thus, the husband's education level may exert somewhat less influence than it formerly did over a wife's perceptions and decisions. Certainly, since a woman's education was significantly related to her perceptions of what her husband and doctor thought, one might speculate that a woman could be taking control in negotiating reality in the direction she perceived to be in keeping with her definition of the situation. Rather than adopting a passively compliant stance, women may increasingly be, as Menzies (1982:39) paraphrased it, "creating their own destinies, though not in circumstances of their own choosing." Thus, the impact of the husband's education level may be somewhat reduced.

The number of children respondents had showed no direct or indirect relationship to the dependent variable. Given the significant trend in the posited direction (rejectors had somewhat larger families), it is conceivable that with a larger sample size, this measure could have achieved statistical significance in logistic analysis. Alternatively, it could be that as family size in America has dropped overall (Westoff, 1977), number of children may no longer be a relevant measure to investigate in genetic counseling research.

The variable assessing previous and/or present divorce status was included largely on an exploratory basis. Davies

(1983) had suggested this could be an important factor and, extrapolating from Stryker's (1959) symbolic interactionist account of marital relationships, the variable was posited to be a measure worth investigating. Present findings suggest, however, that divorce status may be relatively unimportant and should be considered in future research on an exploratory basis to discern whether its lack of significance here was an artifact of non-random sampling procedures.

Although decisions relating to amniocentesis have been characterized as highly personal, emotional, and individualistic, it appears that a fairly pragmatic economic factor may also influence counselees' behavior. While not of primary importance, a person's ability to finance this medical procedure may subtly affect the final decision. This is consistent with Sanders' (1982) discussion in which he stated that people may refuse treatment if their self-esteem or self-perceptions are threatened by an inability to pay for medically-incurred expenses. Such an interpretation may be especially salient given the context of the situation. At University of Iowa Genetic Clinic, anyone who chooses to undergo amniocentesis will be tested, irrespective of ability to pay or insurance coverage. If a physician recommends it, or even if the woman herself seeks amniocentesis to allay her concerns, the procedure will be

performed. While this suggests there are no structural barriers per se, it is possible that some individuals would prefer to forego amniocentesis rather than acknowledge their inability to pay.

There are two additional considerations that may explain the strong indirect influence of insurance coverage. First, this measure may in fact be capturing socioeconomic status, that is, those with fairly extensive insurance coverage may have higher incomes and more prestigious jobs. If this is the case, insurance coverage represents an indirect measure of socioeconomic status. Thus, as socioeconomic structural barriers have been somewhat reduced in recent years, this measure may no longer directly affect decision outcome, but it does, nevertheless, influence perceptions, definitions of the situation, and interactions with significant others, all of which are directly related to the behavior these women chose.

A second explanation for the significance of insurance coverage may simply reflect sampling bias. Inasmuch as respondents were selected on a nonrandom basis, it is conceivable that the sample included an over-representation of individuals with insurance coverage for the procedure who also elected to undergo amniocentesis.

Because the meaning of insurance coverage in relation to acceptance of amniocentesis cannot fully be determined,

it would be best to err on the side of pragmatism and suggest that it be treated as a measure of some sociostructural and/or perceptual barrier. Thus, if the medical community and society in general set acceptance of amniocentesis as a highly desirable goal, economic constraints may have to be addressed.

Overall, given the fairly modest influence of education and insurance coverage, variables used to measure the respondents' social identity or perceptions of self may have been improperly selected. One could readily argue that these represent sociostructural, not self-identity, concepts and that given the theoretical guidance of symbolic interactionism, these measures were not sufficiently "sensitized" to the situation. Given Stryker's (1980) and Rosenberg's (1981) conceptualizations of "positions" and "achieved attributes," these measures were employed with the belief that they would indeed contribute significantly to the explanation of the women's behavior. In the future, however, researchers using symbolic interactionism as a guiding framework should perhaps select more social-psychological measures of self-perception to determine whether self-esteem, locus of control, or self-concept variables may prove to be more salient to final decisions made by genetically at-risk individuals.

Quite serious problems with multicollinearity make the

influence of reference groups and significant others somewhat difficult to assess. Examination of bivariate relationships showed that a woman's husband, doctor, and friends each exert moderate to considerable impact on her final decision. In all the analyses, however, the woman's perception of what her husband thinks appears to be by far the most significant predictor of her acceptance or rejection of amniocentesis. This is not at all surprising given the preponderance of literature suggesting that husbands exert substantial influence on the decisions couples make. As Bernard (1973) has noted, husbands, who generally hold more power and control within the family, most often make the final decisions in important matters.

When interpreting the significance of the husband's opinion about amniocentesis, however, two very important considerations must be kept in mind. First, and most importantly, whether the husband thought his wife should have the procedure was assessed from the respondent's point of view. A woman who interpreted her husband's opinions within the context of her own biases and perceptions would undoubtedly have a personal stake in perceiving her spouse to hold views consistent with her own. Even women who stated that their husbands had left the decision up to them may in fact have been characterizing their husbands' opinions as sufficiently neutral to allow them to do what

they wanted to do. Numerous studies support this interpretation. Wilkening and Morrison (1963) found husband-wife consistency in decision-making items to be only 50.0%, with agreement ranging from a low of 36.0% only up to 77.0% (considerably lower than the reported 84.4% consistency of acceptor husband-wife dyads). Others have likewise found substantial disparity between husband and wife responses and/or ability of any one person to assess what the other spouse's decision was (Cromwell and Cromwell, 1978; Booth and Welch, 1978; Brinkerhoff and Lupri, 1978). As Bokemeier and Monroe (1983:646) concluded,

> Findings of husband-wife inconsistency on decision making draw into question the reliability of one respondent's perceptions of another's attitudes, perceptions, or family interaction patterns.

Realizing this, within the present study it is essential to regard the question about the husband's opinion as a measure of the woman's perception of her spouse's viewpoint, which may or may not reflect his actual opinion. When applying such research to real-life genetic counseling situations, those who wish to increase the utilization of amniocentesis among at-risk women may in fact only have to try to influence the woman's perception of her spouse's viewpoint; until further definitive research can measure disparities or consistencies between husbands' and wives' choices regarding amniocentesis, the woman's personal views

and her interpretation of her spouse's perspective must be considered the most significant predictors of acceptance or rejection of the procedure.

Having delineated constraints placed on the interpretation of a measure assessing the husband's opinion from the wife's perspective, there is nevertheless some indication that even when both husband and wife are consulted about matters relating to family planning, the woman's perspective is more consistently related to actual outcome. Beach et al. (1976), for instance, found that the wife's rather than the husband's motives for and expectations of family size were more reliable predictors of reproductive outcomes. Neal and Groat (1976) and Fried et al. (1980) similarly suggested that wives exert more influence on couple fertility behavior than do husbands. How one interprets these discrepancies, however, is a matter of perspective. Some symbolic interactionists have argued that wives and husbands construct shared definitions of their marriage through their interactions. Bagozzi and Van Loo (1980) claimed a couple's perceived utility of children is a mutually reinforced construct that emerges through husband-wife interactions. Given this interpretation, disparities between spouses' reports are characterized as "measurement error" of the reality of the marital dyadic relationship. Thus, researchers who argue that wives-only

models are misspecified because when models are reanalyzed including husbands' as well as wives' views, significantly more variance in couple fertility behavior could be found (Fried et al., 1980; Townes et al., 1980) can be countered by those who insist upon a measurement error explanation:

> husbands' reports partially correct the estimated correlation coefficient for attenuation due to measurement error; the "increase" in explained variance simply reflects the addition of a second, error-ridden measure of the same true variable reflected in wives' responses (Thomson and Williams, 1982:1000).

Based on this premise, it could be that in this study wives' reports are largely representative of the couples' joint decisions, more indicative of actual behavior, and that discrepancies reflect methodological, not substantive, errors. This would be consistent with a common sense assessment of the situation in which husbands, too, have a large investment in the outcome of their wives pregnancies, and therefore undoubtedly do exert considerable influence on the final decision.

The highly significant bivariate relationships of a doctor's opinion and support for the woman's decision regarding amniocentesis is not unexpected in light of previous findings from genetic counseling research (Lubs, 1979; Dixson et al., 1981). Medical practitioners exert considerable influence on an individual's definition of the situation, not only because they are often perceived as

having knowledge and expertise, but because they are generally viewed as authority figures as well. Moreover, as Iams et al. (1983) noted, when interactions with doctors are based on a longstanding relationship, patients often trust and respect their doctor's views. The meaning that emerges from a consultation thus is affected by the medical professional's opinion and influence.

The same caveats apply here as those delineated with regard to questions assessing the husband's opinion (i.e., reports by the women themselves may or may not accurately represent the doctor's actual opinion or support). However, the response patterns of acceptors and rejectors suggest that the women's reports conceivably reflect the actual doctor's behavior. A disproportionate number of rejectors (77.8% of the 36 asked) claimed their doctors had left the decision up to them; in contrast, just 26.2% of the acceptors characterized their physician's opinions as neutral. This may signal the impact of medico-legal considerations. Doctors holding reservations about or biases against amniocentesis could be adopting a stance of neutrality since the spectre of malpractice and civil action suits (such as "wrongful birth" cases [Donovan, 1984]) restricts their ability to express negative views about the procedure. Thus, unlike the question measuring husband's opinions, where a majority (60.0%) of the rejectors'

husbands were reported to hold views consistent with the woman's behavior, only 8.3% of the rejector's doctors reportedly said they didn't think their patient needed amniocentesis. Thus, it appears that a doctor's active support for amniocentesis, not passive neutrality, will exert a large influence on the woman's final decision. These different response patterns may merely reflect women's bias in perspective, but more probably they suggest that this interpretation captures the essence of what transpired in these doctor-patient interactions. Women may tend to go to medical practitioners who have somewhat similar perspectives and, within small communities, perhaps quite similar backgrounds. Thus, women who chose not to undergo amniocentesis may have had the implicit approval for their decision from doctors who were like-minded. In the end, the women's reports of their doctors' support and opinion may in fact reflect the actual opinions and practice behaviors of the medical professionals who are themselves influenced by personal attitudes, norms, and concerns about the legal implications of their advice.

Neither support from parents or friends and neighbors was significantly related to decision outcome in multivariate analysis (although the latter was found to be significant in bivariate logistic regression). Possibly the questions were too general and added specificity would alter

the measured influence of these significant others and reference groups to decisions made under conditions of reproductive uncertainty. However, irrespective of nonsignificant outcomes in multivariate analyses, these two questions revealed important information. A large minority of women facing difficult decisions regarding pregnancy outcomes do not discuss their concerns with others. More than a third of the respondents had not talked about their decisions with their parents and four in ten elected not to confide in friends or neighbors. Without further information, it is impossible to ascertain the underlying cause for this behavior. It could reflect the personal choices of these women who may feel decisions relating to reproduction are totally private matters. Or, their reticence may signal respondents' perceptions that these reference groups and significant others would express negative reactions because amniocentesis is still viewed as a potential precursor to abortion (Verp and Gerbie, 1981; Davies and Doran, 1982). In the United States, where abortion has only been legal subsequent to the Roe v. Wade Supreme Court decision in 1973, normative sanctions against abortion still hold considerable weight. As Bundey (1978) noted, in Sweden, where abortion has been legal for more than 40 years, few women referred for chromosome analysis due to increased risk of congenital disease refuse

amniocentesis. Whether in time American normative standards will likewise accept amniocentesis and, if necessary, abortion, and whether this will in turn influence at-risk women to seek support for their decisions from a wider network of support groups remains to be seen. What is clear is that amniocentesis itself and the potential it holds for abortion are both new practices in American society for which normative standards have not emerged. Indeed, some social scientists have found abortion to be viewed as "deviant" behavior (Rosen and Martindale, 1980), which could then evoke negative reactions from reference groups and significant others. It is possible these women were defining the situation such that they felt discussing their circumstances with others would not afford them emotional support, but would possibly exacerbate their own uncertainties.

Another way of interpreting the reticence reported by a large number of respondents can be extrapolated from Schulz and Rau's (1985) conceptualization of life course events. They suggested a typology in which stress-inducing situations may be temporally and statistically normative (e.g., marriage), temporally nonnormative and statistically normative (e.g., becoming widowed at a young age), temporally and statistically nonnormative (losing one's job), or temporally normative and statistically

nonnormative. It is into this latter category that women at genetic risk fall. As Schulz and Rau perceived it, temporally normative and statistically nonnormative events are those that occur within an expected time frame but are experienced by relatively few people. They (1985:133) noted, "Because such events occur infrequently, neither the victim nor the support network acquires the specific knowledge and skills that might be useful in coping with the event." Thus, the women at genetic risk may simply feel that their parents and/or friends and neighbors would not be able to offer support or guidance in relation to a nonnormative event for which no standards have evolved. Lippman-Hand and Fraser's (1979b) work gives this interpretation credence. They reported that one-third of the women in their qualitative study appeared to be searching for a normative standard or comparison group from which they could gain guidance. They (1979b:121) quoted one woman as asking,

> Are there others like us? What do people do with this risk? Do they take the chance? ... We've never had to face this kind of thing before, so want to know what others say.

The measure of religious strength appeared to exert no direct influence. Rejectors were considerably more likely than were acceptors to characterize the strength of their religious preference as "very strong" (42.0% vs. 26.6%).

However this question may in fact be too general. Despite Goettsch's (1984) findings that religious strength in general increases opposition to abortion, it may be that this measure was unable to differentiate between those whose strong religious preference engendered antiabortion norms and those whose strong religious preference fostered a situation-ethics approach. The more specific question relating the influence of religious teachings to abortion, on the other hand, demonstrated a highly significant relationship in the bivariate analysis and when part of a three-variable index, exerted significant direct and indirect influence in the multivariate analyses. In the future, assessing the impact of religion with situation-specific, rather than general, measures may offer a more meaningful approach to determining the influence of religious reference group norms.

Women's interpretation of their genetic-risk status and chances for complications associated with the procedure all proved to be highly significant predictors in bivariate analyses. This underscores the necessity for researchers to focus on the individuals' perceptions and definitions of the situation rather than trying to ascertain why objective, statistical probabilities appear to exert so little influence on behavioral outcomes. In multivariate analyses, when controlled for by other variables in the model, it

appears that a woman's estimation of the chance of complications she would be willing to accept to undergo amniocentesis is by far the most significant "risk assessment" predictor of acceptance of amniocentesis. In this sample, a remarkably large percentage (52.0%) of the rejectors versus none of the acceptors asserted that amniocentesis would be acceptable only if there were no chance of complications (i.e., no chance of spontaneous abortion). This measure is of major importance, and may be interpreted as capturing not only the woman's definition of the situation but the strength of her motivation as well, in that those willing to accept higher risks are apparently more strongly motivated to be aware of and perhaps avert the possibility of bearing a child with genetic disorders.

The two interpretation-of-risk measures that were not significant in any multivariate analysis suggest that both acceptors and rejectors do, in fact, have a fairly accurate definition of the situation. Neither acceptors nor rejectors assessed their risks of having a child with Down as extremely high. Despite the advanced maternal age of the majority (78.7%) of respondents, and though the incidence of Down syndrome increases dramatically with age, this is a fairly accurate perspective. Using Hook and Chambers' (1977) estimated risk rates, even the oldest respondent (age 47) had a 5.0% chance of carrying a fetus with Down, and the

rest of the women 35 and older as a group had risk rates ranging from 0.3% to 3.1%. Obviously it is a matter of interpretation, but an objective appraisal of risks of 5.0% or less would suggest that this is, indeed, only a very low to moderately low risk, which is where the majority (77.1%) of the respondents placed themselves. Similarly, the women's estimation of risks of complications was fairly accurate, that is, none of the respondents perceived the risks associated with amniocentesis to be very high. In multivariate analyses, then, because both groups evidence similar trends, when controlled for by other more powerful measures in the model, these two questions failed to demonstrate significant influence on decision outcome.

The women's perceptions of the test's accuracy in diagnosing a fetus with Down syndrome proved to be highly significant in the bivariate analysis, somewhat significant in subset full sample multivariate analysis, and indirectly significant in the final full model analysis. This could be expected in that women who chose amniocentesis understandably perceived the test to have very high accuracy (77.4%); in contrast, only 46.0% of the rejectors perceived the test's accuracy to be very high. While not as strong as the other directly-significant risk variable, this measure nevertheless would seem to be a useful predictive variable for inclusion in future research designs.

Finally, that the abortion norms and attitudes index proved to be so significant in multivariate analyses confirms the prevailing perception that amniocentesis is indeed related in many people's belief systems to abortion and, further, that attitudes and norms become highly relevant in situations where individuals will have to act either in conflict or concordance with their personal normative structures. Although eliminated from the final parsimonious model due to the strength of the other variables, the abortion attitude index nevertheless exerted considerable, significant indirect influence through what the respondent perceives her husband to think and her willingness to accept chances of test complications. This has a strong intuitive appeal in that attitudes and norms causally influence a woman's perceptions about her husband and her willingness to accept chances of complications, which in turn will directly affect her behavior. Hill's (1981) review of attitude-behavior research noted that attitudinal and behavioral measures are often unrelated or inconsistent as a function of the lack of specificity of the attitude measure. That is, general attitudinal reports may have little perceived relevance to women facing a highly personal decision. However, the index of abortion norms and attitudes used here appears to judiciously tap both global and situation specific norms, values and attitudes that are

perceived to be relevant and in fact do either directly or indirectly influence the behavior the woman adopts. This measure, then, would seem to be an important index to incorporate into future research.

Limitations of the Study

While only selective support was found for the four detailed hypotheses investigated in this study, the underlying conceptual framework is significant and useful. There are, however, certain factors that may have influenced the outcome. Inasmuch as subjects were drawn from a nonrandom sample and largely from residents of Iowa, generalizations to other at-risk individuals may be somewhat circumscribed. Moreover, despite efforts to combat it, problems with multicollinearity may have artificially reduced the models, thereby eliminating important factors that could exert significant influence on decision outcome.

Certainly, given a symbolic interactionist framework and interpretation, one must remember that responses were elicited to structured, forced choice questions. Findings thus reflect a finite part of the respondents' interpretations of meaning, norms, attitudes, and values. Only information that could be tapped within the confines of a 30-minute period of interaction is available for analysis. Qualitative and/or longer-term assessments would probably

reveal more complex relationships among factors leading to the women's ultimate behavior.

Rejectors, who were often interviewed in their homes, at a less stressful time, and at a slightly later period in their pregnancy, may have responded somewhat differently had they been interviewed at the same time and in the same place as were the majority of acceptors. Inasmuch as subjects generally experience a gradual deterioration of recall accuracy (Schlesselman, 1982), rejectors' more so than acceptors' responses may reflect an element of recall bias, which, given their behavioral outcomes, could be colored as much by rationalizations for their actions as by their recollections of their actual original perceptions. Further, as 42.0% of the rejectors received genetic counseling and/or information from different physicians than did the rest of the sample, the emergent meaning created in these doctor-patient interactions may well have been different.

In short, differences in setting, definitions of the situation, and the medical professionals with whom the women interacted must be taken into consideration. Responses that appear to reflect different interpretations of meaning may in fact tap situations that <u>were</u> different, in which case one would not expect their answers, behaviors, or interpretations to be consistent with those in dissimilar

counseling situations. Nevertheless, responses from acceptors and rejectors suggest basic underlying differences in perceptions and significant other influences should be replicated in future studies.

Implications and Applications

That education and insurance coverage exert indirect influence holds only limited implications for change. Higher educational status not only to increases the likelihood of having insurance but also may affect husband-wife definitions of the situation (or, at least, the wife's perception of her husband's opinions). In general, education represents underlying socioeconomic status factors. Altering basic social structures is not a readily achievable goal, but at least part of the structural constraints could be mitigated either by the provision of Medicaid coverage or sliding-fee scales for amniocentesis or by an increased awareness that those who want to undergo the test will be able to do so irrespective of their ability to pay. This would remove the financial barriers that could be deterring more widespread acceptance of the procedure.

The influence doctors exert suggests that efforts should be increased to include more medical genetics courses in medical school curricula. This would seem to be particularly advisable as the post-World-War II generation,

many of whom postpone pregnancy until later in life (Thorton and Freedman, 1983), enter the increased risk of advanced maternal age. A majority of doctors receive negligible training in the field of genetics (Sorenson and Culbert, 1979; Reilly, 1979). As obstetricians, gynecologists, or family practitioners are generally the first medical professionals with whom prospective parents interact, these physicians need to be aware of the genetic factors that could adversely affect pregnancy outcome and should have at least a rudimentary ability to convey their concerns in such a way that patients recognize genetic counseling and amniocentesis as possible preventive measures they could consider using.

Perhaps the most practical implication and application of the present study centers on acknowledging the importance of the counselees' definition of the situation. Objectively, acceptors and rejectors had very similar risk rates. All received identical information sheets delineating their at-risk status and 228 of the respondents interacted with the same geneticist and nurse clinician. Clearly, however, acceptors chose a different method of coping with this information than did rejectors. These findings suggest that a spouse and doctor may exert a great deal of influence either in reality or at least perceptually. Thus, genetic counselors should maintain good

communication linkages with practicing physicians throughout the area to be sure appropriate referrals are being made. Further, efforts to include husbands in genetic counseling sessions could result in their gaining first-hand knowledge of genetic risks which, according to Emery et al. (1979), would at least increase the likelihood that risk probabilities would be retained. The extent to which this would affect behavior is somewhat in question, but it is reasonable to expect an increase in the factual information base couples share.

Abortion attitudes and norms appear to affect intervening variables more so than the acceptance or rejection of amniocentesis itself. Attitudes and values are often derived from group interactions (Fiske and Taylor, 1984); the norms of significant reference groups, on which attitudes and values are usually based, constantly, if slowly, undergo transitions. According to adoption and diffusion theories, this suggests that increased knowledge about and utilization of amniocentesis will make it more normatively acceptable. For individuals reluctant to undertake a new, nonnormative behavior, this change could enable them to accept genetic testing. The medical community, as a prestigious and powerful social institution, could facilitate and promote normative structure changes through more media exposure, advocating the use of

amniocentesis via documentaries, circulars, and public service announcements.

Second, as antiabortion attitudes may deter some eligible clients from seeking amniocentesis, medical practitioners should continue to underscore that amniocentesis and abortion need not be linked. Once this becomes clearly understood, utilization of genetic testing could potentially increase. The advantages of this are three-fold. First, those who are carrying an affected fetus would have more time to prepare emotionally for the child's birth. Steinmarc and Wieting (1983) noted that anticipatory psychological preparation can play an adaptive role. Foreknowledge could perhaps give parents more time to develop the coping skills required in caring for a handicapped child. Second, once made aware that they are carrying an affected fetus, women who previously opposed abortion might alter their perspective. This is not to suggest abortion is the right choice; rather, the emphasis is on the option <u>of</u> choice while alternatives are still available. And third, in the vast majority of cases, amniocentesis test results provide assurance that the fetus is, in fact, normal with respect to the hereditary or genetic defects in question. In the present study, only 5 abnormal fetuses were detected. Thus, for the other 194 women, amniocentesis provided a sense of reassurance that

the child would not have Down syndrome or another disorder that could be diagnosed prenatally.

Finally, genetic counselors need to be conscious that perceptions--of risks, of test sensitivity, of susceptibility, and of others' reactions--exert a large influence on outcomes. Although there is no clear-cut way of altering perceptions, some suggestions can be offered. A lack of social comparison groups for nonnormative events may distort or alter perceptions. Certainly, the statistical infrequency of genetic defects places at-risk parents in a sort of isolation, sans norms, experience, or role models. By bringing together individuals who must deal with the reality of their at-risk status, prospective parents may be able to put their risks in perspective. These social comparison groups could potentially affect the counselees' definition of the situation. Learning how others are coping with the uncertainties of pregnancy outcomes or the burdens of raising children with genetic disorders could provide at-risk couples with real-life information that may assist them in reaching a decision. Lippman-Hand and Fraser (1979b:61) quoted a counselee as saying, "I'd like to meet someone else who is [affected]. Have they had children? What problems have they had?" Cues for behavior in an unanticipated situation could be derived from the reactions and responses of other similarly-affected individuals.

These social-comparison groups could also evolve into a support system that might alleviate some of the tensions, anxieties, and concerns related both to the decision and, if this option is selected, to the genetic testing procedure itself.

Suggestions for Future Research

Data in the present study and their interpretation represent the perspectives of the at-risk women involved. There is no way to ascertain the actual opinions and behaviors of the husbands, doctors, parents, friends, or neighbors. The research was undertaken with the full understanding that the analysis would focus on the woman's own "reality," which is an important area to explore. However, future research should also endeavor to investigate others' perspectives as well.

The primary way in which genetic counseling research should be modified and improved would be the inclusion of husbands' responses. Examining perceptions and definitions of the situation of both husband and wife could provide very useful information. If it were indeed confirmed that women's reports of their husbands' opinion were largely reliable, this then would provide a useful way of assessing both husband-and-wife views of amniocentesis. On the other hand, if a basic discrepancy between husband and wife

reports exists, genetic counseling studies should always include husbands as well as wives to more accurately assess the decision-making processes of couples at genetic risk.

This suggestion is not without recognized problems. The obstacles that most readily come to mind are financial and time constraints. Analysis of data from more than one family member significantly increases both cost and complexity of a study. More time is required to arrange for interviews with the husband as well as the wife. If interviews are conducted in the home, having two interviewers would probably be advisable; thus, personnel costs could also escalate. Understandably, many researchers elect to interview the most accessible family respondents which, despite an increase in female employment, is still generally the wife.

However, a more salient and perhaps less remediable problem would need to be addressed. Ever since Safilios-Rothschild (1969:290) railed against the pervasiveness of "wives' family sociology," researchers exploring dyadic marital relationships have attempted to solicit information from both husbands and wives. The present research was in fact proposed with the intention of gathering information from both spouses so analyses of husbands' and wives' responses could be explored. It soon became apparent, however, that interviewing male subjects

was highly problematic.

The majority of individuals who attended the Genetic Clinic during the sampling time frame were the pregnant women themselves. Though most were married (in the present sample where such information is available, 91.6% were married and living with their spouse), women generally came in alone for genetic counseling. Most of these women undoubtedly relayed the information they received during counseling to their husbands. But this creates the confounding factor that husbands' opinions evolved based on how their wives presented the information, a presentation that would inevitably reflect the woman's definition of the situation. Thus, had more men been interviewed, husband-wife responses may have been "artificially" consonant since the meaning that emerged from their joint interactions would be predicated only on the wife's interpretations of the genetic risk information she had received.

In addition to these methodological and theoretical concerns, men's failure to attend genetic counseling simply made them less accessible to being interviewed. The principal investigator's annual progress reports repeatedly noted the difficulties interviewers were experiencing in obtaining male respondents. At the end of the two-year interview period, only 51 husbands of the 199 acceptors had

been solicited for participation. Far more problematic were the husbands of rejectors. Only 9 agreed to be interviewed. Thus, while one can readily point out the necessity of including husbands in reproductive decision studies, clearly, this is not so easily implemented in real-life situations.

Another, and probably more feasible, way in which future research could be improved revolves around the questions themselves. Much of the literature refers to the threat to identity people at genetic risk experience when confronted with this information (Corgan, 1979). Others have mentioned feelings of shame, guilt, and stigmatization of a carrier (Kessler et al., 1984; Tishler, 1981; Kenen and Schmidt, 1978). In future research, more salient, situation-specific questions, including self-perception measures, should be incorporated.

As with most research, it would be ideal to have prospective measures of the individual's sense of self before at-risk status was known so the measures could accurately gauge the extent to which reception of at-risk information affected the individual's self-image. Drawing upon the "decision tree" specified in Figure 1, it would also be useful to ascertain changes is self-perceptions as individuals pass through each of the stages where decisions and choices can be made. Examination of at-risk individuals

over a longer period of time would offer the potential of testing Goffman's (1963) concept of a "spoiled identity." Research could determine whether at-risk status does, indeed, affect self-image and, if so, for how long. For instance, would women feel stigmatized just in relation to their current pregnancy, during the full scope of their reproductive years, or would this carry over into other facets of self-image which would in turn have a longstanding impact by significantly altering the woman's self identity. It might be speculated that the latter would be true. Certainly, Kenen and Schmidt (1978) believed this to be the case. Female role socialization may exert considerable influence in this respect. Rhetoric regarding women's changing roles and the reality of increased participation in nondomestic spheres of life notwithstanding, the importance of childbearing to women's concept of self cannot be negated. Research continues to indicate that for many women, the ability to have children--and this implies healthy, normal children--is still a very strongly-held value. Straits (1985), for instance, found that middle-class college women believed commitment to motherhood should take precedence over career aspirations if the two were in conflict. Straits (1985:594) concluded that "lifestyle values are much more traditional than one would expect based on journalistic accounts of changes in young

women's career and reproductive intentions." How at-risk status would affect long-term evaluations of self, expectations, values, and behavior is an area that needs to be examined.

Conclusions

In many respects, amniocentesis offers prospective parents a means whereby they can exert an element of control in planning their families. Placing the importance of genetic screening in perspective, Galjaard (1979) noted that in modern countries, where improved hygiene, sanitation, socioeconomic status, and medical care have eliminated most fatal infectious childhood diseases, congenital malformations and genetic disease have currently become the most common cause of infant mortality and morbidity. This is not the only impetus for an increased interest in amniocentesis, however. Galjaard (1979:343) explained:

> Other reasons are the decreasing family size, the increasing independence of women, the availability of new methods of diagnosis and prevention, and the increasing costs of optimal medical and social care of the handicapped.

Amniocentesis also has the potential to reduce the number of parents facing the enormous emotional and financial burden of caring for a seriously disabled child. Factors that relate to its utilization among genetically at-risk individuals would then seem a worthwhile goal. It

is hoped this study will further the exploration and application of amniocentesis towards that end.

EPILOGUE

In 1957, Straus suggested that medical sociology had become divided into two separate but closely related areas: sociology *in* medicine and sociology *of* medicine. He characterized the differences in terms of the perspectives employed by each group. Sociologists in medicine, he noted, were motivated by medical rather than sociological problems, and used applied, often atheoretical methods and analyses to investigate the research question at hand. The origin of health disorders, often in relation to sociostructural variables, was the focus of the research and the audience or clients were usually medical professionals themselves or larger governmental agencies such as the U.S. Department of Health and Human Services. Guided by the priorities of the health-care perspective and frequently funded by nonsociological sources, the medical sociologist's objective was to investigate areas that would have direct applicability to patient care, public health, and governmental policies.

Sociologists of medicine, in contrast, more often relied on a sociological, theory-driven perspective to analyze and explain the social processes that take place within medical environs. They examined the organization,

roles, norms, values, and beliefs of medical settings, expecting their research to further their discipline's understanding of social life in general.

Cockerham (1986), among others in medical sociology, no longer believes these distinctions are useful. He (1986:2) noted that

> contemporary medical sociologists are less concerned with whether or not a piece of work is in the sociology of medicine or sociology in medicine, but rather with how much it increases our understanding of the complex relationship between social factors and health.

The previous five chapters have taken the latter view, attempting to isolate factors that explain facets of consumer behavior within a medical setting. However, embracing the fusion of the two disciplines as if they were one tends to obscure some fundamental differences between medical and sociological perspectives. Further, while the hybrid has proven to be advantageous to both professional communities, periodically it is advisable to assess what is happening here (as did Emerson [1970]) from a sociological perspective. Rosengren (1980:111) asserted, "...medicine and social science differ in profound organizational and metatheoretical ways." Within this epilogue, some of these differences will be explored.

The first section will critically appraise the merit of the research question of the present dissertation within the context of the real world. The impact medical technologies

exert on society as a whole and on specific individuals exposed to these medical procedures will be examined. Within the second section, some of the ways in which the practices, methods, and interpretations of research problems differ between medical and sociological practitioners will be delineated. In the final section, conclusions about the future of medical sociology will be discussed.

The Research Question

The impact of genetic diagnostic procedures can potentially affect not only the individuals involved but larger social institutions as well. Although there are numerous aspects that could be developed, two major areas relating to the social consequences of this new medical procedure will be outlined.

Bioethics

The necessity for and importance of sociological participation in examining the social and ethical implications of advanced medical technology cannot be underestimated. In an era when surrogate motherhood, recombinant DNA genetic engineering, and organ transplants are technological realities, it is essential that social scientists become involved in delineating the sociological consequences these progressive techniques may exert on individuals and the society. Yet, as Fox (1979) pointed

out, sociologists to date have made only limited contributions to the examination of these important issues. She (1979:423) noted, "Most sociologists have not chosen to concentrate on the kinds of problems with which bioethics is concerned and are unaware...of its potential sociocultural import." Fox suggested several reasons for this lack of sociological input: sociologists may feel these questions are best left to cultural anthropologists; they may hold ideological convictions that work against defending or analyzing supposedly entrenched, conservative values and beliefs; or they simply may not have the training or expertise required. Speaking to the last concern, Fox (1979:424) expressed her belief that

> some ability to handle the relationship between sociological variables...and biological, biomedical, philosophical, theological, and/or legal variables...is requisite.

This would suggest a broader, more interdisciplinary approach to sociological training than is usually practiced in colleges and universities. Finally, the field of bioethics has not enthusiastically welcomed the few sociologists who have tried to become involved. Fox (1979:424) charged that the gatekeepers of this emerging discipline, generally composed of philosophers, theologians, biologists, and lawyers, perceive sociologists as too "scientific" and "insufficiently humanistic."

Despite these barriers, sociologists should, and almost

inevitably will, become involved in these bioethical discussions, if for no other reason because they are integrally involved in research centering on medical technological applications. As Gibson (1983) noted, at least a third of the professionals within health associations are sociologists. Thus, sociologists are not only observers of but participants in these new medical experiments.

Technological advances often hold dual potentials. Amniocentesis is a boon to parents who wish to avoid bearing physically or mentally disabled off-spring. When used to this end by individuals who want to exert some control over their reproductive chances, the development of prenatal screening would seem to be a social good. Accordingly, the research question examined here--identifying factors that relate to acceptance or rejection of amniocentesis--is beneficial to the extent that efforts to modify prospective parents' access to, knowledge of, social support for, and perceptions of risk attendant to amniocentesis could increase the utilization of this service. There is evidence to suggest this medical tool is also being used for goals that may be perceived as socially or ethically questionable, however. Jeffery et al. (1984), for example, noted that in India, where male rather than female children are highly desirable, amniocentesis is being used as a technologically

"condoned" form of infanticide; pregnant women who learn that their baby is female may abort the child. The prevalence with which prenatal screening has been used to avoid giving birth to female children has prompted some medical practitioners in India to suggest the banning of the procedure entirely. Nor is abortion due to sex preference confined to a particular culture. To the contrary, Elliott (1979) found that while not commonplace, the request for amniocentesis to choose the sex of a child has been encountered by physicians in every major medical center in the United States. Elliott predicted this practice will become even more prevalent as population pressures increase and the public becomes more aware of this potential service.

In addition to the use of amniocentesis to select the preferred sex of a child, the procedure has also been requested by some parents in an attempt to screen out any and all genetic defects. Redmon (1981) noted the value conflicts experienced by genetic counselors who interact with clients wanting amniocentesis and, if necessary, abortions for relatively minor and currently remediable conditions.

Problems relating to these questionable requests for abortion and amniocentesis cover three major areas. First, the social consequences of sex selection are indeterminate. In societies where female status is very low, the use of

amniocentesis to abort female fetuses could create major sex-ratio imbalances. In the United States, sex selection probably would be less likely to produce seriously unbalanced male-female ratios, although Coombs (1977) found that the majority of women preferred a son to a daughter and were more likely to desire one sex than to have an equal number of boys and girls. However, Westoff and Rindfuss (1974) had noted that most couples preferred having a male child first, female second. How the long-range consequences of sex-related genetic engineering would affect social institutions is a question that requires the exploration of sociologists and should be considered before amniocentesis is widely advocated and accepted. For example, will the status of female children be further jeopardized in society and, if usually second-born, will they have less economic and emotional support from their parents than that enjoyed by a first-born male child.

Second, sociological investigation into the consequences of seeking amniocentesis for sex selection and for minor as well as major defects should also be undertaken in relation to how these requests affect the medical practitioners involved. The dilemma is complicated by the fact that genetic counseling and "therapeutic" abortion are advocated by geneticists and physicians in situations where prospective parents have a high risk for producing children

affected with serious life-threatening and/or disabling diseases. However, are the known risks associated with amniocentesis (0.2% to 1.5% likelihood of miscarriage [Cruikshank et al., 1983]) justified in view of parents' desire to have the procedure, whether for severe genetic risk, mild, correctable anomalies, or preference for a certain sex? Further, when trying to assess the social good of avoiding the birth of a seriously-affected child, at what point can a distinction be made between quality of life potentials for genetically-affected individuals? As Emery et al. (1979) noted, prospective parents with conditions perceived as debilitating by "normal" people may, in fact, feel that bearing a child with a similar disease is perfectly acceptable. Perceptions of parents who have a genetically-affected child are also at variance with popular conceptions of what types of diseases are to be avoided. Elkins et al. (1986), for example, found that among women requesting amniocentesis who already had given birth to a Down syndrome child, only 25.0% said they would consider undergoing an abortion should the test be positive. This, Elkins et al. (1986:183) asserted, is indicative of "a failure to recognize the generally positive response of women to their children with Down syndrome." Finally, as Reynolds et al. (1974) noted, genetic screening is not advocated for potentially serious diseases such as diabetes

or heart conditions, which suggests that some diseases are more socially acceptable than others, and that doctors and geneticists counseling prospective patients very often rely on personal value judgments and socially-defined norms to determine whether a particular genetic malformation would warrant the termination of a pregnancy.

Given these complexities, it becomes imperative for sociologists working within genetic counseling situations to be aware of the possible consequences attendant to their participation in research. If amniocentesis and abortion are held to be morally acceptable from a societal perspective in some cases and not in others, at what point can or should physicians and genetic counselors interject their personal values into the procedure? Since Roe v. Wade (1973), there are no legal barriers behind which the medical community can hide. To the contrary, the increasing numbers of "wrongful life" suits point to the necessity for medical practitioners to provide "accurate, appropriate genetic counseling, diagnosis, and testing" upon request (Hecht, 1983:98); Donovan (1984:69) underscored this by noting that the Supreme Court's decision ensures a person's "constitutional right to decide whether or not to have a child and that this right includes the right...to terminate a pregnancy by abortion." Physicians and medical institutions that view a request for amniocentesis as

"frivolous" (e.g., avoiding the birth of a girl) are potentially faced with lawsuits. How this legal reality affects the prevalence of genetic counseling and diagnosis and the actions of the medical personnel involved requires the investigation of sociological researchers.

Perhaps most importantly, sociologists need to investigate how the availability of this diagnostic procedure is dispersed throughout the social structure. Preliminary research suggests that amniocentesis is more readily used by higher socioeconomic groups. It is incumbent upon sociologists to ascertain whether these socioeconomic differences are due to financial or educational barriers or a lack of medical facilities accessible to lower status groups. Inequalities in access to genetic screening may, in fact, be yet another indication of a society ridden with inequalities of class, race, and gender (Burke and Kolker, 1984). Further, sociologists need to determine whether the incidence of higher socioeconomic groups demanding amniocentesis for sex-selection or to reduce maternal anxiety is thereby reducing the availability of the services to lower socioeconomic groups that may need prenatal diagnosis for detecting major debilitating conditions.

Sociologists can explore the ethics, goals, and consequences of this technological intervention (Kelman and

Warwick, 1978). By attempting to objectively examine empirical evidence, irrespective of their personal values or biases (Gouldner, 1968), they can ascertain whether genetic testing and abortion are being unduly advocated by genetic counselors and legislators for certain groups of clients over and above other groups. For instance, due to a lack of understanding about the distinction between sickle cell carrier status and the disease itself, many states in the 1970s rushed to pass laws mandating the screening of blacks for the disease, using the information to bar affected blacks from educational or employment opportunities (Fletcher, 1981). Goodman and Goodman (1982:20) suggested that Jews are often the target of "overselling of genetic anxiety" in which massive genetic screening programs have been undertaken to avoid the incidence of Tay-Sachs disease. Besides discriminating against certain groups, genetic screening also holds the possibility for invading the privacy and labeling or stigmatizing individuals who have are found to have a potentially damaging genetic trait (Goerth, 1983; Murray, 1983).

In summary, sociologists working in research that explores means of increasing the acceptance of genetic testing must also be aware that the procedure has a dual potential. Amniocentesis can provide concerned parents with a relatively safe method for reducing their likelihood of

producing a seriously disabled child. At the same time, the procedure can be used for altering sex ratios, reducing the number of individuals with relatively minor genetic diseases, placing some medical practices and practitioners into roles they perceive as morally untenable, and contributing to inequalities in the present social system.

Medicalization of pregnancy

In addition to the emergence of numerous bioethical issues related to amniocentesis, there are indications that the procedure exerts pressures on individuals in the planning of their families as well. Cockerham (1986:11) pointed out that "medicine is both a solution and a cause of many social and individual problems." There are few areas of life not touched by medical practices or opinions. According to some medical sociologists (Twaddle, 1969, 1973; Freidson, 1970), medicine is actually an institution that is concerned with controlling deviance, which within the medical community is a synonym for illness. Szasz (1974:44-45) noted that over time, more and more functions and behaviors were classified as illness by medical communities until doctors "...began to call 'illness'...anything and everything in which they could detect any sign of malfunctioning...no matter what the norm."

Applying this perspective within the context of the

current study, the prevalence and advocacy of genetic diagnosis has the potential for, and in fact has already begun, expanding the extent to which medical and technological practices control the lives of prospective parents. Rothman (1983) suggested that the increased use of amniocentesis has culminated in the direct intrusion of technology and larger social institutions into the personal, individual domains of pregnancy and childbirth. Wertz and Wertz (1977) have likewise expressed concern that the widespread use of amniocentesis not only holds the potential for endangering the health of mothers and babies, but also tends to alienate women from their own pregnancy and childbirth, making it a medical rather than personal event.

Feminist sociologists have described the consequence of this medical expansion into heretofore private domains (Fox, 1979). Some of them perceive this intrusion as an attempt to take away the mystery and female powers attached to procreation with the goal of turning pregnancy into a male-dominated arena. Reissman and Nathanson (1986) have described the way in which the "management of reproduction" has come about by a social construction of risks and responsibilities attendant to childbirth. They noted that medical science defines pregnancy as a "problem," using such terms as "low-risk" and "high risk" to characterize a naturally-occurring event, and thereby equating it to

disease. Following from this premise that all pregnancies in some way include "problems," the medical community can then offer the "solution." In the case of prenatal diagnosis, the medical answer is the advocacy of widespread genetic screening for individuals with "high-risk" pregnancies.

There are two major concerns regarding the medicalization of pregnancy. First, the dominant perspective of the medical community pervades the lives and beliefs of prospective parents. The rhetoric of geneticists and physicians suggests that medical progress in the form of amniocentesis offers women a choice. Most clinics openly express the conviction that amniocentesis should be available to anyone who requests it, regardless of whether that individual believes she would undergo an abortion in the event a defective fetus was detected. In reality, however, genetic screening would very shortly cease to exist and funding would not be forthcoming for studies if the majority of women undergoing amniocentesis did not, in fact, use the information to abort genetically-affected babies. The genetic counseling paradigm continues to extol the virtue of preventive techniques. Terris (1979:95), for instance, noted that screening tests should be relatively cheap, easy to do, have high specificity and sensitivity, and "should be done only if the disease they uncover can be

treated effectively." To doctors, given the current state of technology, the only "cure" for a genetic disease in an abnormal fetus is abortion. The medical community talks about a prolife bonus attached to amniocentesis, expressing the view that women who might formerly have abandoned the hope of bearing a child will now become pregnant with the anticipation that prenatal diagnosis will allow them to abort a genetically-affected fetus (Roghmann and Doherty, 1983). The perspective that this represents a "cure," however, is diametrically opposed to the perception held by individuals who view life as beginning at the moment of conception and who believe abortion is morally wrong. The prospect of engaging in a procedure that tacitly condones abortion is unconscionable to these individuals. Even prospective parents who have fewer moral or ethical objections nevertheless react to the technological procedure with a wide range of generally negative emotional responses.

How the medicalization of pregnancy affects the women involved has been the focus of several studies. Phipps and Zinn (1986a,b), Fava et al. (1983), and Antley (1977), for instance, demonstrated that women undergoing amniocentesis experience anger, hostility, depression, and anxiety. Lippman-Hand and Fraser (1979b:61) revealed the extent to which counselees are torn by the conflict between their personal desire to have a child and their concern about the

information geneticists have imparted to them, quoting a patient as saying,

> I don't know how the medical profession expects us to react and behave in this situation...I don't want to go ahead...and have everyone, the doctors basically, shaking their heads and saying, "What a fool, doesn't she know this isn't done?"

Silvestre and Fresco (1980:617) similarly noted that women in their study tended to perceive the doctor performing the amniocentesis as "holding the power to permit or prevent their child's being brought into the world." Desperately wanting to have a baby, they feel they have to rely on medical professionals who "closely intervene in the manufacturing and validating of their child" (Silvestre and Fresco, 1980:617).

Ironically, this sense of loss of control over a formerly personal event may be amplified, albeit unintentionally, by genetic counselors who stress the "chance" nature of the occurrence of genetic defects. The motivation of the counselor is largely that of removing a sense of guilt from the perceptions of the prospective parents involved. The consequence, however, is that the counselee experiences this information as a further loss of control over the situation (Lippman-Hand and Fraser, 1979b). A parallel may be drawn with attribution research exploring the beneficial effect of perceived behavioral control on individuals' coping abilities. As Bulman and Wortman (1977)

and Janoff-Bulman (1979) noted, behavioral self-blame gives an individual the impression s/he can exert control over the outcome of negative experiences in the future. For prospective parents, the explanation of the "chance" incidence of genetic defects implies that they cannot affect what will happen. Thus, women at genetic risk must, to some extent, relinquish control over the outcome of a pregnancy to highly skilled medical professionals. At this time, prenatal diagnosis, in conjunction with the willingness to undergo an abortion if necessary, is the only means available to improve their chance of avoiding the birth of a genetically-affected child; it in no way guarantees that the child will, indeed, be healthy or that future children will be normal.

In addition to forcing prospective parents to submit to the control and intervention of medical practitioners, amniocentesis places a further emotional burden on the individuals involved. First, because the procedure is best performed between the 15th and 18th weeks of pregnancy, the mother has already experienced the presence of her unborn child as a very real entity. Often, the fetus has started moving, and the pregnant mother has felt and responded to the life growing within her. Moreover, since amniocentesis is done in tandem with ultrasounds, prospective parents can view the unborn child in the form of sonogram images.

Although somewhat indistinct, these pictures add to the recognition that the unborn fetus is a living being. The "bonding" that takes place between mother and child due to these procedures makes the prospect of abortion even more difficult (Brewster, 1984). Finally, the anxiety of the whole process is further exacerbated by the waiting period, which can extend from two-and-one-half weeks up to six weeks, adding to the difficulty women encounter when contemplating the abortion of their unborn child should the tests come back positive (Burke and Kolker, 1984).

These findings suggest that while genetic screening has the potential for relieving the concerns of prospective parents, there is at the same time a strong possibility that pregnant mothers will feel powerless, experience high levels of stress, and will respond with feelings of deep resentment toward the intrusion of technological and medical practitioners into the normatively anticipated "natural" progression of conception into pregnancy, and to the delivery of a child who is expected to be normal. In effect, this medical advance has permitted the consolidation of control the medical establishment exercises over areas that were formerly personal, private domains.

The ways in which amniocentesis can undermine the emotional security and sense of control among the prospective parents has begun to be the focus of medical

sociology research. What is less well understood is the long-range impact this procedure will exert on social norms and expectations. Rothman (1983:8) stated that "prenatal diagnosis presents an...example of the phenomenon of cultural lag; the technological progress of the past ten years has not been matched by social research." Specifically, social scientists need to examine the effect increasing advocacy and utilization of genetic diagnostic tests may have on social norms. Amniocentesis could conceivably become incorporated into the social structure as a socially-desirable practice. Promoters of the procedure have noted the huge financial savings that would accrue from the widespread use of amniocentesis. Saul et al. (1980) calculated that expenses related to performing 100 amniocenteses, in which three abnormal results were obtained, would come to $65,000, whereas the cost of lifetime care for one seriously-disabled individual could average $500,000. It is important to note that in their calculations of costs for performing 100 amniocenteses with three abnormal results they included the expense of three abortions. Cost analyses of this nature clearly represent the deterrence of bearing a genetically-affected child as unquestionably desirable from an economic standpoint, thereby removing the focus from the personal to the social good realm (Kessler, 1980). Lorenz et al. (1985:935)

similarly concluded that "the most cost-effective model for pregnancies in women over 35 is 100% utilization of genetic amniocentesis and termination of all affected pregnancies." They acknowledged, however, that the prospective client of amniocentesis may view the whole process in less financially-pragmatic terms.

Meanwhile, Crandall et al. (1986) and others have suggested that the procedure should not be relegated to women 35 and older, but should be advocated for younger pregnant women as well. If amniocentesis increasingly becomes the norm and is viewed as socially desirable, what will be the social consequences for an individual who, because of strong personal moral objections to abortion or an overriding desire to have a child, refuses to undergo the test? Will the parent then been held accountable for the care of the child should it have mental or physical disabilities that could have been detected and "eliminated" before birth? Will parents of genetically-affected children become bereft of social comforts and aid, or suffer the curtailment of financial assistance because they didn't take the "appropriate" preventive action? Will they be further stigmatized because fewer parents will be facing the same difficulty of coping with the burden of a physically or mentally handicapped child?

If social pressures prevail and most at-risk couples

undergo genetic screening and abort an affected fetus, this further reduces the chance that they will be able to produce "normal" offspring. With each subsequent attempt, the parents will be older (which means at higher genetic risk) and may be less able to conceive, since fecundity has been shown to decrease with advanced maternal age (Menken et al., 1986). In addition, because they have already conceived a genetically-affected child, risk rates are recalculated accordingly. For example, a couple may initially be assessed as having a 1.0% risk; after the birth or abortion of an affected child, their known risk increases to 3.0-5.0%; after the birth or abortion of a third genetically-affected child, the couple's risk is calculated at 10.0-12.0% (Carter and Roberts, 1967).

At what point, then, will society "allow" parents to risk continuing a pregnancy in which an affected fetus has been diagnosed, given the couple's hope that the manifestation of the disease in their child will be manageable and perhaps, eventually, correctable when further technological developments occur? Just because an advanced technology exists, does it mean people are obliged to use it? The question becomes even more salient in light of the fact that approximately 45.0% of the Down syndrome fetuses detected prenatally would, in fact, have never been born; Hook (1978) estimated that nearly half of these pregnancies

end in spontaneous miscarriage--an event prospective parents find difficult, but which doesn't entail the anxiety, guilt, or shame associated with the intentional termination of a pregnancy due to results obtained from amniocentesis.

Sociologists need to be in the forefront of assessing the social consequences of increased medicalization of pregnancy. They should attempt to forecast the extent to which social control exerted by medical technology will be incorporated into the normative mainstream--and, in so doing, address the possible consequences these normative pressures and sanctions may exert on the at-risk parents involved.

Freeman (1983) noted that many sociologists working within applied sectors are motivated by the hope that they could contribute to the good of society. He (1983:25) cautioned, however, that

> [w]e cannot expect that the sheer brilliance of our ideas, the scientific weight of our data, or the charisma of our personalities will overcome social forces moving in a direction contrary to our values. On the other hand, if we understand social trends and diagnose needs and opportunities arising out of changing conditions, we can make small but significant contributions to human welfare.

Insofar as medical sociologists are in a position to examine the social forces surrounding the advent of prenatal diagnosis, it is important that they contribute their perspective and knowledge to the growing body of bioethical

literature. Further, as social scientists are accustomed to exploring the impact of social institutions and social norms on individuals, it is essential that they begin to analyze both beneficial and negative consequences attendant to the proliferation of amniocentesis for prenatal diagnosis.

Practices, Methods, and Perspectives

Although sociologists and medical practitioners have been able to collaborate on fairly extensive research, this does not imply that the two disciplines have mutually interchangeable perspectives, practices, and theories. The current dissertation was undertaken with the cooperation of a physician who is also an epidemiologist. As Cockerham (1986:14) defined it, epidemiology currently is "concerned with exploring human ecology as it relates to the health of human beings and their environment." To the extent that epidemiologists are somewhat more closely related to social scientists in their methods and perspectives than are many medical practitioners, the disparity between the two disciplines was considerably reduced. Had this research been implemented by one of the more "traditional" divisions of medicine, this dissertation may have consisted of trying to extrapolate generalizations from the findings of laboratories, petri dishes, or experimental designs in an attempt to apply these results to real-world situations.

Fortunately, given the emphasis of an epidemiologist's training, the current study was employed with the objective of examining a variety of social-psychological as well as demographic factors as they affect individuals seeking or rejecting amniocentesis. Despite this mutually-advantageous collaboration between sociological and epidemiological perspectives, there are certain trends that prevail in medical research that do not obtain as frequently in sociological studies.

Data collection/sampling

Perhaps the most tangible difference between sociological and medical research techniques can be seen in the selection of participants or respondents for investigation. Epidemiological research tends to sample from available populations. Particularly when researching a certain disease or a fairly rare health condition, it is difficult to employ random sampling techniques. It would generally require a massive number of contacts to find a reasonable number of respondents who evidenced the medical problem being studied. In the United States today, three of every 100 babies are born with serious genetic defects (Adler, 1987b). The incidence of Down syndrome in the general population is one in 121. In the current study, had a random sample been undertaken, it would have required contacting at least 8,300 females to obtain a sample size of

249 genetically at-risk women. To study Down syndrome exclusively, independent of age, 30,129 women would have to be interviewed before a sample size comparable to the one in the present study could have been identified. When medical or epidemiological studies investigate more prevalent diseases or behaviors, such as cancer or smoking, a potential exists for conducting a random sample in which sufficient numbers of people at risk for the problem being studied might be identified. However, medical researchers largely rely on the already diagnosed population at hand.

In this study, 228 women were fairly easily identified and solicited for participation in the study because of their referral to the genetic clinic at the University of Iowa Hospitals and Clinics. However, recruiting the additional 21 women who refused to undergo amniocentesis required considerably more effort. Letters were twice sent to all practicing obstetricians and gynecologists in the state of Iowa. This reliance on the cooperation of medical practitioners not involved in the study presented problems of bias over which the researchers could exert no control. There was no way to assess the extent to which eligible patients were told about the study but refused to participate. Nor was there any concrete method for determining the extent to which the cooperating obstetricians and gynecologists selectively asked their

patients if they would be willing to participate in the study. Thus, this study, as with much medical research, relied on accessibility and availability rather than random samples. The lack of a truly random sample must then be taken into account when making generalizations about the findings. This is not to suggest that sociologists base their predictions and estimations solely on information gained from random samples. However, in general, medical researchers are more often forced to rely on nonrandom samples than are social scientists.

The manner in which participants are solicited for inclusion in a study also suggests a distinction between sociological and medical research. The foci of medical studies are health and disease as they are manifested in the general population. Again, however, because of financial and time constraints, medical researchers tend to approach "captive" patients who are already experiencing the condition in question to conduct their research. How respondents react to being asked deeply personal and probing questions that are presented to them during very stressful periods in their life cannot be fully measured. However, Hawkins (1958) suggested that ill people and especially those who are hospitalized tend to give socially desirable or incomplete answers and are often too irritable or unable to respond with truly reliable answers. While not captives

to the extent that inpatient respondents are, respondents in this study were nevertheless interviewed at a time when they were dealing with considerable anxiety or stress relating to the outcome of their pregnancy.

Sociologists have similarly studied people during very personal, private, or painful times in their lives (e.g., Lopata, 1973). However, research exploring grief attached to the death of a loved one, asking questions about intimate sexual practices, or probing to learn more about the burdens associated with caring for a disabled child is far from the norm.

The acquiescence of potential subjects solicited for participation as they keep medical appointments or are hospitalized points to yet another difference between medical and sociological research. Patients who are asked to cooperate with a medical researcher are always expressly informed of their rights; they have the right to refuse to be a respondent, the right to decline to answer any question they object to, and the right to withdraw at anytime. They are also assured that their answers will be treated in strictest confidence and that their participation or refusal to participate will in no way affect their medical care or treatment. On the surface, this would appear to afford ample opportunity for individuals to refuse; in reality, subjects who are physically and/or emotionally distressed

have less ability to decline. Those who still require medical services may feel pressured into participating for fear of negative reactions from health professionals for their refusal to cooperate with the researcher. Finally, because contacts are frequently made in face-to-face situations, patients will often comply with the request to participate despite their inherent reluctance to do so. There is, then, a subtle coercive force at work in many medical research projects.

In contrast, sociological researchers frequently rely on telephone or mail surveys. In the former, persons asked for their cooperation have fewer compunctions about turning down the request of an unknown, invisible researcher with whom they will probably never have interpersonal contact. Far more so, mail questionnaires can be summarily ignored. Even in face-to-face contacts, potential respondents would not be concerned that the researcher could somehow create problems for the individual who needed assistance in health-related matters. Those approached for participation in sociological studies are thus freer both physically and psychologically to refuse to comply with the researcher's requests.

Another reason medical researchers may have more opportunity to solicit the participation of potential subjects hinges on the credibility and legitimacy with which

their research is perceived, not only by patients but often by the general populace as well. Despite recent social trends evidencing the reduction of prestige and authority accorded them, medical practitioners are still viewed with a considerable amount of respect. Research that purports to find new treatments or improve health conditions is generally regarded as worthwhile and potentially useful to the patient involved. In comparison, sociological research is not usually viewed in this light. At best, the popular perception of the sociological enterprise is one that confuses sociologists with social workers. More often, sociologists are characterized as individuals who go about investigating what "everyone knows anyway." Accordingly, potential respondents asked to volunteer their time and opinions may feel little obligation to do so. For example, as an interviewer, I often encounter more resistance from patients when they are asked basic demographic questions, which seem to be perceived as intrusive and unnecessary, than when they are probed for extensive information about their pregnancies, delivery traumas, or their use of alcohol and drugs.

In light of the previous two distinctions, it is perhaps understandable that medical researchers often solicit cooperation from and therefore come to expect a 90.0-95.0% response rate, even in ongoing longitudinal

studies. Voluntary drop-out rates are severely constrained, as patients, who must return to the medical facility, are often reluctant to withdraw from a study for fear that their treatment or interactions with the doctor may in some way be adversely affected. In contrast, sociological research is often undertaken with the expectation that achieving a 70.0-80.0% rate of participation is both adequate and quite acceptable as representing the population as a whole.

Finally, there is a distinct difference in the way information is gathered from respondents. Few sociologists could conceive of having the time and money to wait for eligible subjects to materialize. The amniocentesis study was conducted over a two-year period during which only 249 interviews with eligible female respondents were completed. The research assistants involved in the interviewing process would wait for indeterminate amounts of time for patients whose appointments with the geneticist were prolonged. They also had to travel to the homes of many of the respondents who refused amniocentesis. In addition, because some accepting respondents didn't want anyone to know of their amniocentesis, interviewers had to arrange for clandestine meetings in hotel rooms to assure respondents that the confidentiality and privacy of their participation and responses would be safeguarded. Face-to-face interviews are always costly and time consuming. They are even more so

when one has no control over the rate at which potential participants will enter into the sampling frame or the time at which interviews can be scheduled and completed. Yet the amniocentesis study was not the exception but rather the rule for epidemiological investigations.

Sociological researchers also have used face-to-face techniques and have had to wait for eligible subjects. However, this type of research has been fairly infrequent and, given financial constraints, is even more rare today.

Methods

While not mutually-exclusive, the methods employed by medical researchers and by sociologists are generally somewhat different. The design of choice among most medical researchers is a case-control study, in which subjects with a particular condition or disease (cases) are matched (often on the basis of age, sex, race, and/or income) with individuals in whom the condition or disease is absent (controls). Also known as a retrospective study design, this method attempts to compare cases' and controls' existing or past attributes or exposures thought to be related to the condition being studied. Ideally, case-control epidemiological studies are conducted by sampling from within a large, geographically-defined population. However, the majority of studies rely on hospital-based case-control sampling frames because of

convenience, accessibility, and financial concerns. The advantages of case-control studies, as outlined by Schlesselman (1982), include the following factors: they can be implemented fairly quickly and inexpensively, require relatively few subjects, allow for the study of multiple potential causes of the disease, are well-suited for the study of rare disease or those with long latency periods, and can benefit from additional information derived from patient charts, which may cover a fairly extensive period of the patient's medical history. Schlesselman also noted, however, that there are distinct disadvantages to case-control designs. Such studies rely on subjects' ability to accurately recall past experiences or exposures, little control can be exerted over extraneous factors, finding healthy individuals to match the cases may be difficult, and validation of information is difficult if not impossible. Also, when such studies are undertaken on a long-range basis, medical practice, usage of technologies, or exposure of subjects to the factors being investigated may change, making findings irrelevant by the time the project is completed.

In many respects, although they often employ different research designs, sociologists are faced with the same dilemmas, particularly with regard to the reliability of respondents' answers in retrospective inquiries and the

inability to control extraneous factors in the environment of the persons being studied. However, sociological studies are generally undertaken acknowledging that, at best, independent variables relating to the dependent variable will be isolated. Unlike medical research, which strives (and often purports) to identify direct, causative agents that result in a disease, sociological research generally reports associations, correlations, and trends rather than claiming to have identified strict cause-and-effect relationships. Sociological research, then, is more often predicated on the concept that the study of human groups involves a wide variety of factors over which the researcher can exert little control. It is generally accepted that by explaining 35.0% or more of the variance, the researcher has identified some fairly powerful predictive variables. In dealing with the lives and health of patients, medical researchers generally require a much larger proportion of explained variance to undertake a new treatment regimen or procedure that also has a potential for adverse side effects.

The analytical or statistical techniques or training of medical researchers is also somewhat different from that of sociologists. Williams (1987), for instance, noted that more than half the residents in her program have no interest in research and know little about statistics or computer

data analysis packages. At one time, few physicians were expected to become involved in research activities; in such instances, the lack of training in methods and statistics would seldom be noticed. Today, however, many medical practitioners are expected to participate in and generate research projects. In many instances, their position with a medical complex may depend on it. If for no other reason, their understanding of the analyses and findings of research published in medical professional journals would be required to keep up with rapidly changing medical technologies. Yet sophisticated "hard science" research methodology is only beginning to be acquired in medical schools. Many medical papers still make predictions based on fairly simplistic t-test analyses between case and control groups.

Sociology has similarly gone through this transitional phase, from being somewhat more qualitative to becoming increasingly quantitative. However, because sociological curricula in most universities enlarged the emphasis on competent study design, computer abilities, and knowledge of statistical techniques before medical facilities did, sociologists are often better prepared than are medical practitioners to organize and conduct applied research.

The conflict created by these different backgrounds in training and expectation has a potential for eliciting tension between the medical practitioner and the

sociologist. Findings that seem fairly significant to a social scientist are considered of dubious merit by a physician. Yet at the same time, medical researchers who draw conclusions from t-test comparisons of case and control groups appear to be naive and excessively reductionist to a sociological researcher. Thus, when collaboration in research is expected to culminate in the publication of several professional articles, different definitions of what is important and what is significant can result in considerable dissent between sociological and medical practitioners coming from different professional disciplines.

Theories and perspectives

Closely related to different methodological training and expectations, disparity between the theories and perspectives of medical professionals and sociologists can be a source of contention. Explanations for these differences can be found in the ways in which members of each discipline were trained for and were socialized into their respective roles.

Medical practitioners function within a close-knit community, which has more stringent, rigid constraints attached to its membership than are often experienced by students aspiring to become sociologists. Rosengren (1980) described it, using Goffman's (1961) terminology, as a

"moral" community, which emphasizes rationality and objectivity. Fox (1979) noted, too, that doctors in training are encouraged to adopt a role of detachment. While becoming involved in some of the most personal, intimate aspects of human behavior and experience, doctors are trained to focus on a specific aspect of their patient; when a patient becomes ill with a disease, many medical practitioners attend just to the body part that is affected by the disorder. This helps them to concentrate on trying to find a cure and also keeps them from becoming too emotionally involved in the day-to-day difficulties the patient is enduring due to the onset of illness.

In contrast, sociologists are trained to use a wholistic perspective. Rather than "dissecting" an individual into parts that can be individually scrutinized, sociologists tend to look at the whole person as well as the environmental influences that are affecting the person. Exposure to theories such as symbolic interactionism, ethnomethodology, and phenomenology prepares sociologists to deal with seemingly "irrational" behavior, because such perspectives recognize that the individual not only acts, but is acted upon, within a complex social ecology; these perspectives also acknowledge that an individual's perception and construction of reality determine the behavior s/he will adopt in a given situation.

In the context of research into acceptance or rejection of amniocentesis, the outcome of these differing perspectives and theoretical biases is readily apparent. Medical researchers conducted extensive research on patient learning of odds ratios and risk probabilities, assuming that if they could divine a way of forcing patients to remember the odds correctly, the prospective parents would make appropriate and rational decisions consistent with the geneticists' perception of reality. Doctors trained to rely on treatments and behaviors that have the best prognosis probabilities are ill prepared to deal with patients not similarly guided in their decision-making processes. Thus, after more than a decade of research on client retention of odds ratios, as well as their subsequent behaviors, published papers were still trying to determine ways in which counselees could be educated to remember and act upon their given risk probabilities.

Only after researchers emanating from more sociological, anthropological, and psychological traditions entered the field did the emphasis shift from objective, rational decision-making models to more subjective interpretations. One could speculate (perhaps optimistically) that had sociologists and social psychologists earlier been involved in these studies, researchers would have more quickly arrived at this

conclusion, and would have modified the research impetus to focus on counselees' definition of the situation and interpretation of meaning within the context of their own lives, expectations, and normative influences.

In addition to attempting to identify the "sensitizing concepts" that would enable them to gain a better understanding of counselees' behaviors, sociological researchers have tended to examine at-risk patients within a larger framework. For medical researchers, the end goal is the "cure," which in the instance of amniocentesis involves avoidance of pregnancy or prenatal diagnosis with the judicious use of abortion to avoid the birth of seriously affected children. A patient's visit to the doctor or hospital is thus often used as the exogenous, independent variable that is expected to be related to the cure of the disease. Sociologists, in contrast, generally perceive health-care visits as the dependent variable, which is affected by a host of independent factors such as socioeconomic status, attitudes, norms, accessibility, availability, doctors' reciprocity, and patient satisfaction. Moreover, social scientists are concerned not just with the diagnosis or the cure, but with the long-term consequences of genetic at-risk status. This would involve following the counseled parents over a longer period of time to determine the extent to which the diagnosis results in a

feeling of stigmatization. In the instance of parents who declined amniocentesis, sociologists would undoubtedly be interested in following them through the pregnancy to delivery and, in the event of the birth of a genetically-disabled child, examining the ways in which the parents cope with this burden.

Finally, the training and socialization of medical practitioners encourages them to deal with uncertainty in such a way that they convey the impression--and in so doing often convince themselves as well--that they are able to arrive at a "correct" solution. In the absence of a clear-cut diagnosis or a foolproof diagnostic procedure, physicians tend to search through their previous experiences for similar situations and then arrive at a conclusion, which is presented as factual and accurate. Sociologists have called this "diagnostic typification" (Rosengren, 1980:102) and recognize that a treatment regimen is not based on hard, scientific, irrefutable evidence, but on doctors' abilities to recall appropriate information, on where they received their medical training, and on their personal biases or judgments. Sociologists have, in a sense, been trained for uncertainty. Within their field, they have learned to accept and expect the unknown and the unfathomable, realizing that research findings are just one of many ways to characterize reality. When professionals

from two different disciplines must mutually arrive at a "conclusion," these discrepancies in perceptions of reality can collide. The physician may believe the results from a research project present incontrovertible evidence that can be generalized, while the sociologist may view the findings as preliminary or insufficiently global in their application. How these differences in interpretations and perspectives can be resolved will depend, in part, on the flexibility and adaptability of the people involved.

Conclusions

Comparisons between medical and sociological research and researchers are not meant to suggest the two communities are polarized. To the contrary, there are probably more similarities than contrasts. Most of the theories, perspectives, methods, and practices of medical professionals have at one time or another been used by sociologists, and social psychological theories and positivistic methods are gaining credence within the medical community. Rosengren (1980) even goes so far as to suggest that the social model is gaining ascendancy, and attributes the gradual demedicalization of society to the increasing influence of the sociological perspective.

The extent to which this is true remains uncertain. What is clear, however, is that medicine and sociology still

have major disparities emanating from metatheoretical and organizational underpinnings that will not disappear. It would be naive to anticipate that cross-fertilization between techniques, strategies, and theories between the two fields would culminate in a multifaceted but unified discipline.

Though each has gained from the exchange, sociology and medicine will continue to experience tensions and conflicts. For sociologists working closely with medical professionals, this means they must learn to deal with dissension and discord. They must also guard against cooptation (Etzioni, 1961), no easy task when employed by the medical community, which is trained to perceive its social construction of reality as truth.

Ultimately, because each discipline can and does gain from one another, the best hope is that their cooperation will result in a healthful, ongoing dialogue and interstimulation of ideas. Fox (1986:29) offered a glimpse of the fruition joint collaboration of medicine and sociology could produce; she suggested that the issues the two disciplines confront help us not only to find logical answers and technical solutions, but encourage us to deal with the "larger questions about who we are, what we stand for, and where we are going as a total society." This would seem an admirable goal for medical sociologists to pursue.

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